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A FOOT IN THE DOOR

A report on the Child Community Care study evaluating the effect of Community Based Organisation support on Child wellbeing in HIV affected communities

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Images used within this report are for illustrative purposes only.

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Where is the evidence?

In 2009, King and colleagues reviewed literature that examined the overall effectiveness of interventions that aim to improve the psychosocial wellbeing of children affected by HIV and AIDS.

Although they did find a number of studies that have looked at interventions, they did not identify a single study that adequately evaluated interventions. Instead it was found that most of the literature gave descriptive reports of the support programs. With limited rigorous evaluative research it is difficult to conclude with certainty whether the psychosocial wellbeing of children affected by HIV and AIDS can be improved by an intervention.

The call for evaluation

In 2009, King and colleagues identified the need for more efficient evaluative research into the effects of interventions on children affected by HIV and AIDS. In 2016, Skeen and colleagues as part of this study, reviewed the literature that has been published subsequent to this and identified 17 new interventions that adequately examined the psychosocial wellbeing of children affected by HIV and AIDS. Fifteen showed benefits of an intervention program. Thus, research is starting to emerge that highlights the benefits of intervention involvement.

Why do we need evaluation?

Although a number of interventions have been identified as attempting to improve the psychosocial wellbeing of children, most assessments have not reported outcome measures, comparison groups, long term follow ups or have been solely descriptive and unable to provide true insight into the impact of these intervention programs. We therefore need efficient evaluation for a number of reasons:

Evidence-based Practice

The integration of expert opinion, hard scientific evidence and client values to create the highest quality intervention programs and services.

Learning from Experience

We can learn what benefits a variety of individuals best, and what works as the most affective and rigorous methods of testing, providing a stepping stone for future evaluative research.

Sharing & Generalising Knowledge

Using the most rigorous evaluative techniques and tools provides us with the ability to generalise and expand evidence out to other populations, where methodology can be replicated to assess the true benefit of an intervention.

Investment

By having adequate evaluation of interventions, we can build up a wealth of evidence supporting how and why we should invest in improving the wellbeing of children.

What are the hurdles?

There are a number of challenges inherent in evaluating community-based programs for children affected by HIV and AIDS.

Skills & Resources

Community based organisations and interventions are located in a variety of communities some of which have limited research capacity. It is also difficult to ensure all staff and data collectors have the same level of skills when working with children and their care givers.

Small Scale

With the limited research capacity of some community based organisations, they are often small in size, with the ability to work with only small numbers of children and cases. Working with only small numbers of children makes it difficult to determine the true effect of an intervention.

Research Bias

Where a number of projects and research are supported by external funding agencies, research may be tied into reporting results to agencies in order to continue their funding.

Balance of Urgency

There is an imbalance in priority given to certain provisions over others. For instance, importance is often given to physical health provisions such as food and medicine over more psychological interventions to meet a more instantaneous need. The longer effects of psychological interventions prove difficult to examine.

Ethical Issues

Randomised control trials are considered a 'gold standard' in evaluating the benefits of an intervention. However, it is unethical to randomly select and withhold an intervention from those in need. It is typically difficult to separate children who have had any contact with an intervention from those who have not.

Other challenges include: high cost, logistical difficulties, blurred lines of provision, complex interventions with several components, varied content and methods of intervention delivery, different types of interventions within community-based organisations.

CREATING THE **CHILD COMMUNITY CARE** STUDY

Creating the Child Community Care Study

Where?

The study collected data from three countries in Southern Africa. The first set of data was collected from South Africa and Malawi. Data has been collected from both these locations at baseline and at a 12-15 month follow up. An additional set of data were collected in Zambia. which contained exclusively baseline measurements. However, it examined an additional set of measures.

South Africa

- Population Size: 52,776,000
- HIV prevalence rate (15-49 years): 19.2%

Malawi

- Population Size: 16,363,000
- HIV prevalence rate (15-49 years): 9.1%

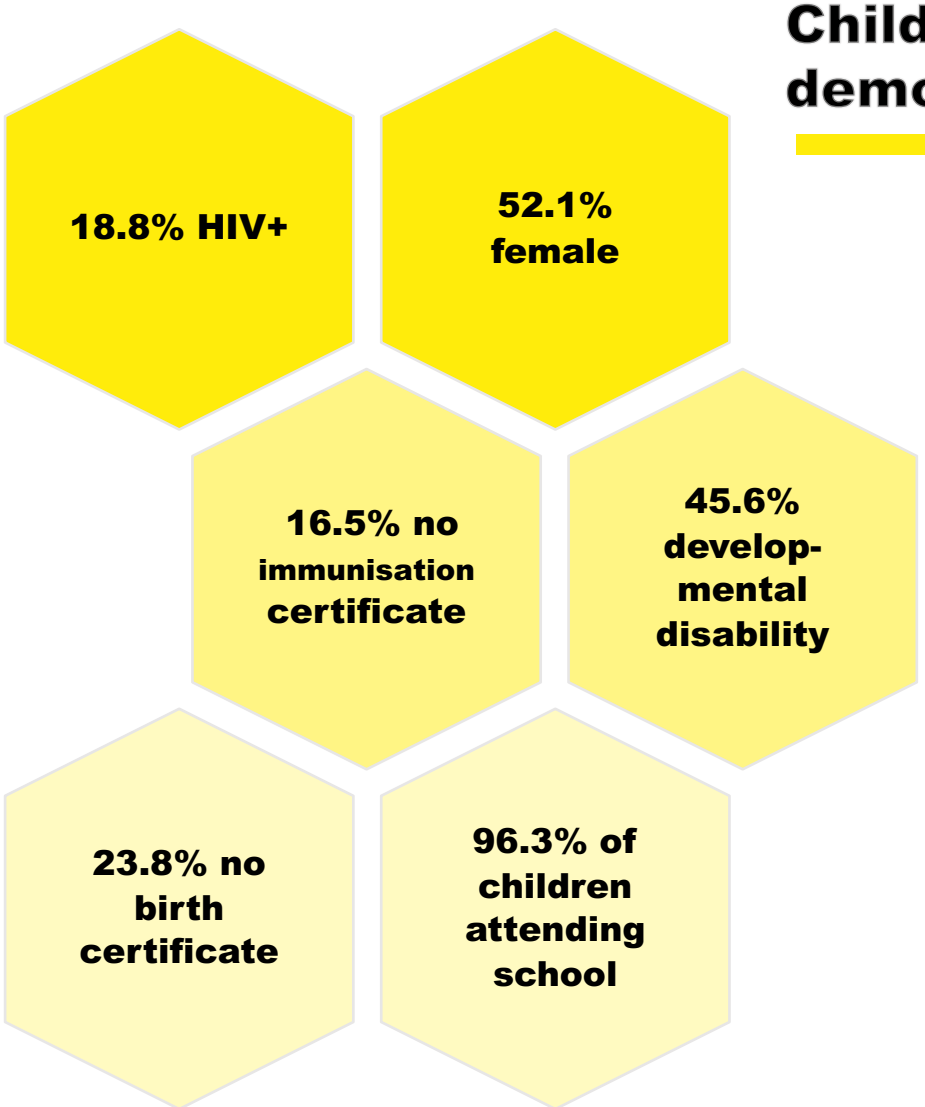
Zambia

- Population Size: 16,212,000
- HIV prevalence rate (15-49 years): 12.9%

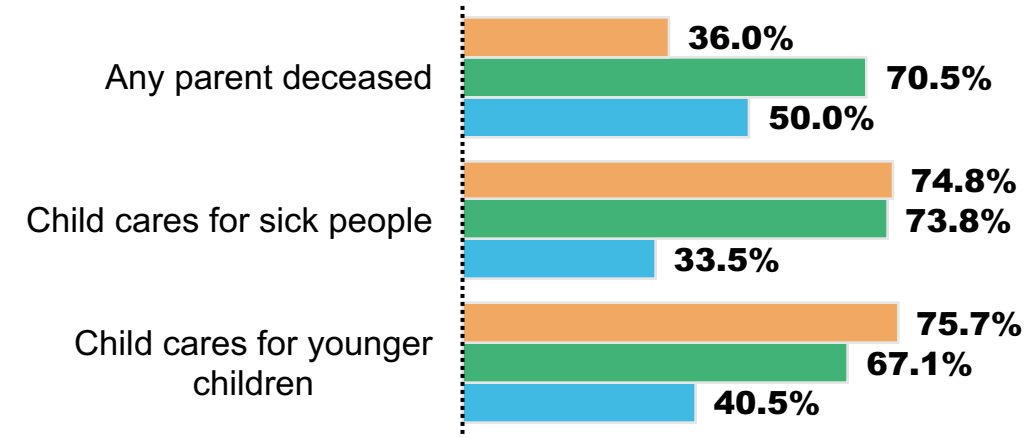
Who?

The Child Community Care study recruited 1228 children aged 4 to 13 years and their caregivers from 34 community based organisation (CBOs). The CBOs were randomly selected from a total of 588 CBOs to reflect the size of the population in each country (see the breakdown below). These were stratified by geography and funder then, using a random selection, generated 24 in South Africa, 4 in Malawi and 6 in Zambia to participate in the study with no refusals.

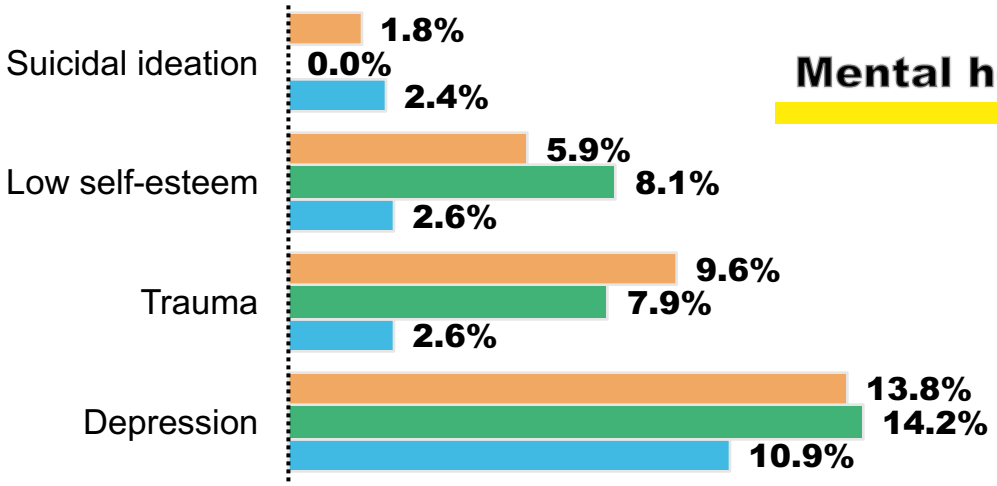
Child demographics



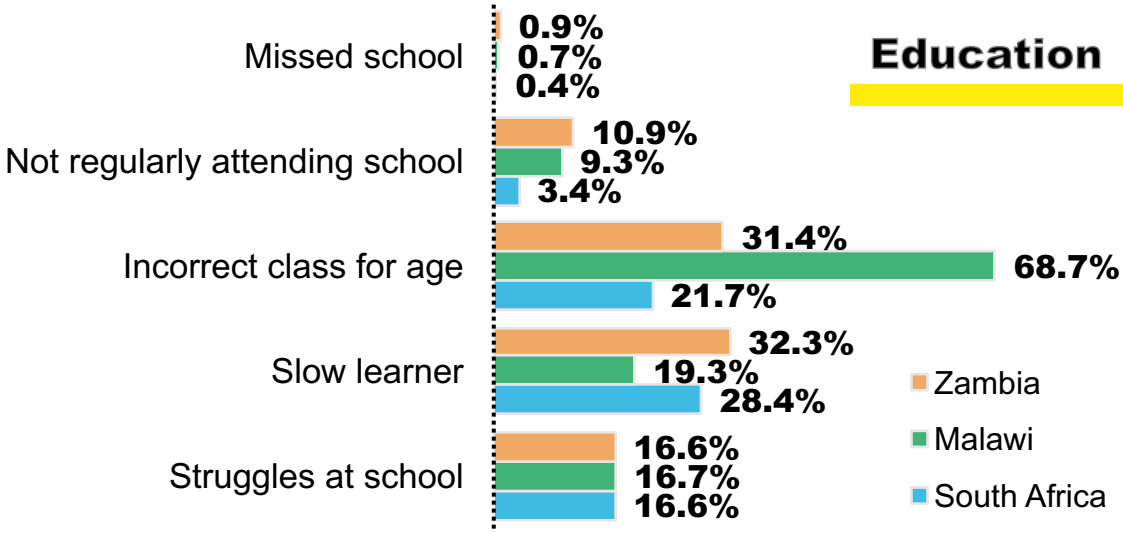
South Africa	Malawi	Zambia
Number of children: **833** Mean age: **8.7 years**	Number of children: **155** Mean age: **10.2 years**	Number of children: **239** Mean age: **9.4 years**



Mental health



Education



Caregiver demographics

89.9% female

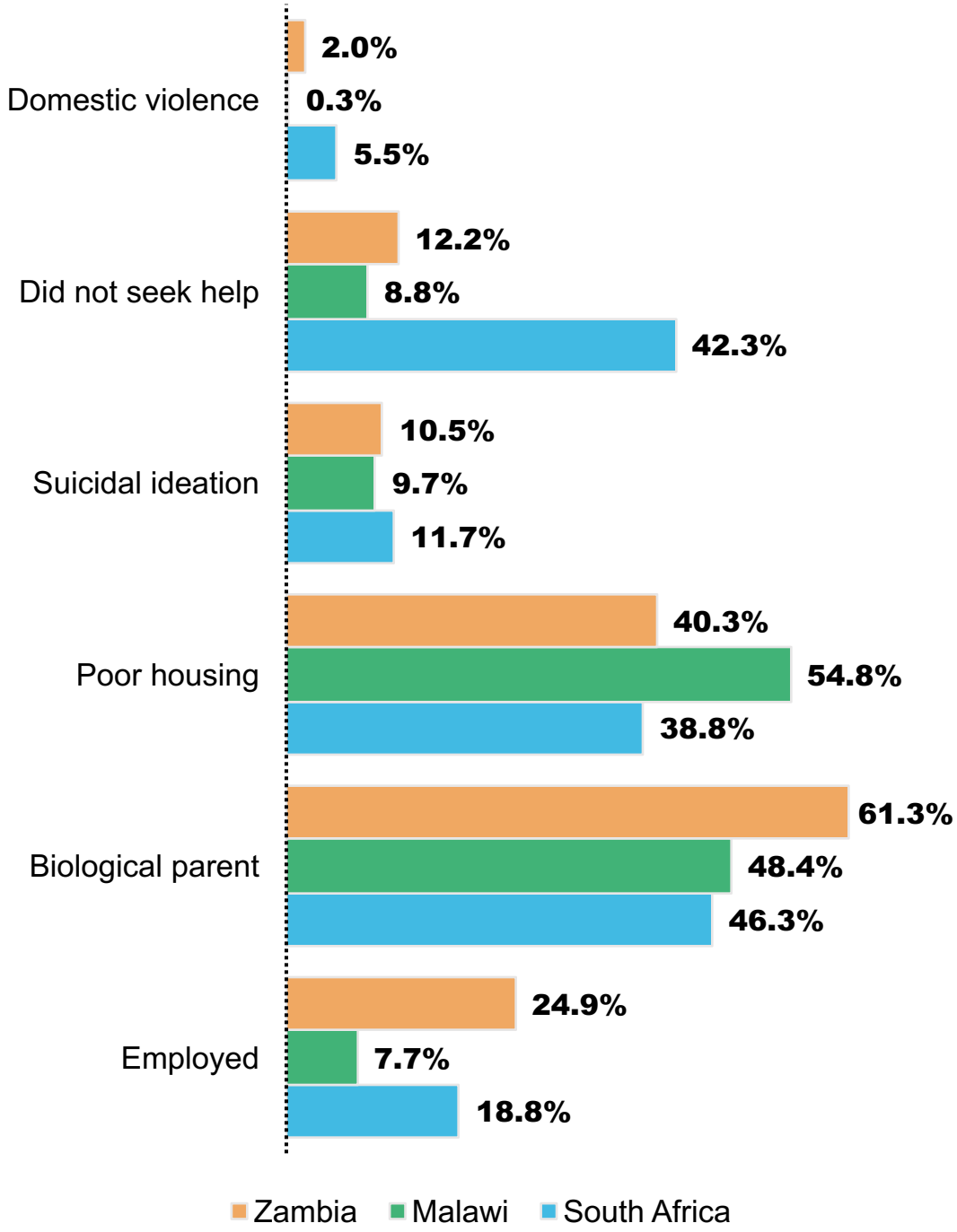
21.7% HIV+

32.9% aged 50 and over

28.3% depression and/or anxiety

South Africa	Malawi	Zambia
Number of caregivers: **797** Mean age: **43.4 years**	Number of caregivers: **155** Mean age: **43.7 years**	Number of caregivers: **227** Mean age: **43.8 years**

Note: Some caregivers cared for more than one child that participated within the study.

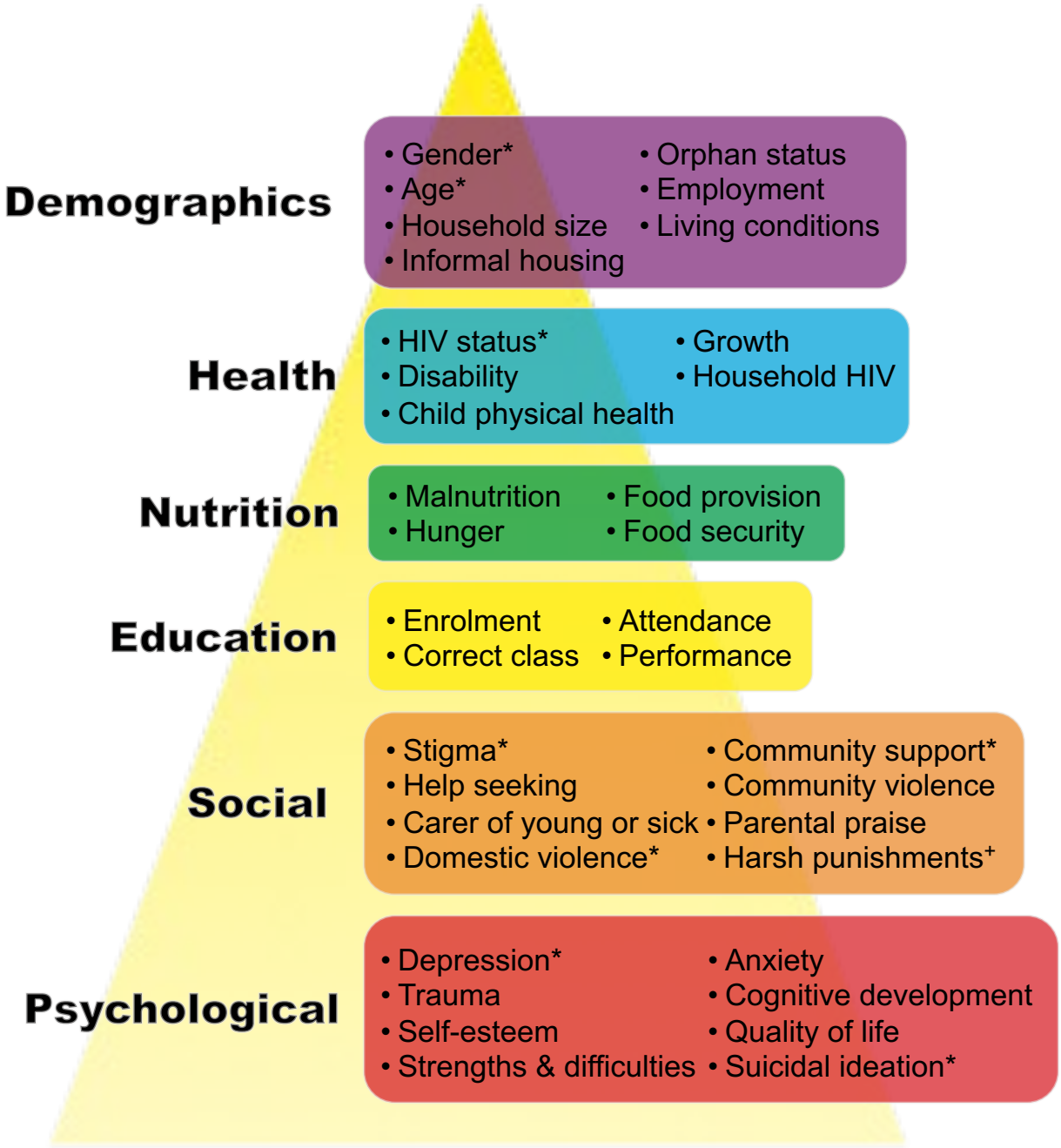


Measures

How?

Children and their caregivers were recruited for all organisations. They were both interviewed separately by trained data collectors who were either fluent in the native language or accompanied by a fluent language speaker. All data were entered into mobile phones and uploaded into a live database. Data on the children were gathered using a combination of self-report from the children and reports from their caregiver. Questionnaires and information reported by both children and caregivers included a range of questions related to child's health, education, psychosocial wellbeing and socio-demographic information. Standardised and validated indices were used. Repeated measures were gathered at follow up (South Africa and Malawi only) to show change over time.

What?



* Measures to both children and caregivers

+ Psychological and physical abuse

Standardised validated inventories were used. See published papers (pp.79-80) for full descriptions.

CBO measures

Staff | Structure | Services

Using a comparison group

Randomised controlled trials are considered to be the 'gold standard' of programme evaluation and provide the strongest evidence for a programme's effectiveness. However, it is often not possible to use a randomized controlled trial (RCT) design in assessing community programmes for children affected by HIV/AIDS. Evaluating programmes such as these requires a practical approach, and the development of studies that are designed to fit into real-world setting

Young Carers Study

Since there was no direct comparison group in the Child Community Care study, we compared child outcomes with those from children who were not receiving interventions enrolled in the Young Carers study.

- 1402 children
- Aged 9-13
- 4 urban and rural health districts
- Over 30% antenatal HIV prevalence

Refusal & Retention

Across both the Child Community Care and Young Carers study there was very few refusals and high number of children retained for data collection at follow up.

Child Community Care study	• Refusal 0.7% • Retention 86.5%
Young Carers study	• Refusal 2.5% • Retention 97%

Community Based Organisations (CBOs)

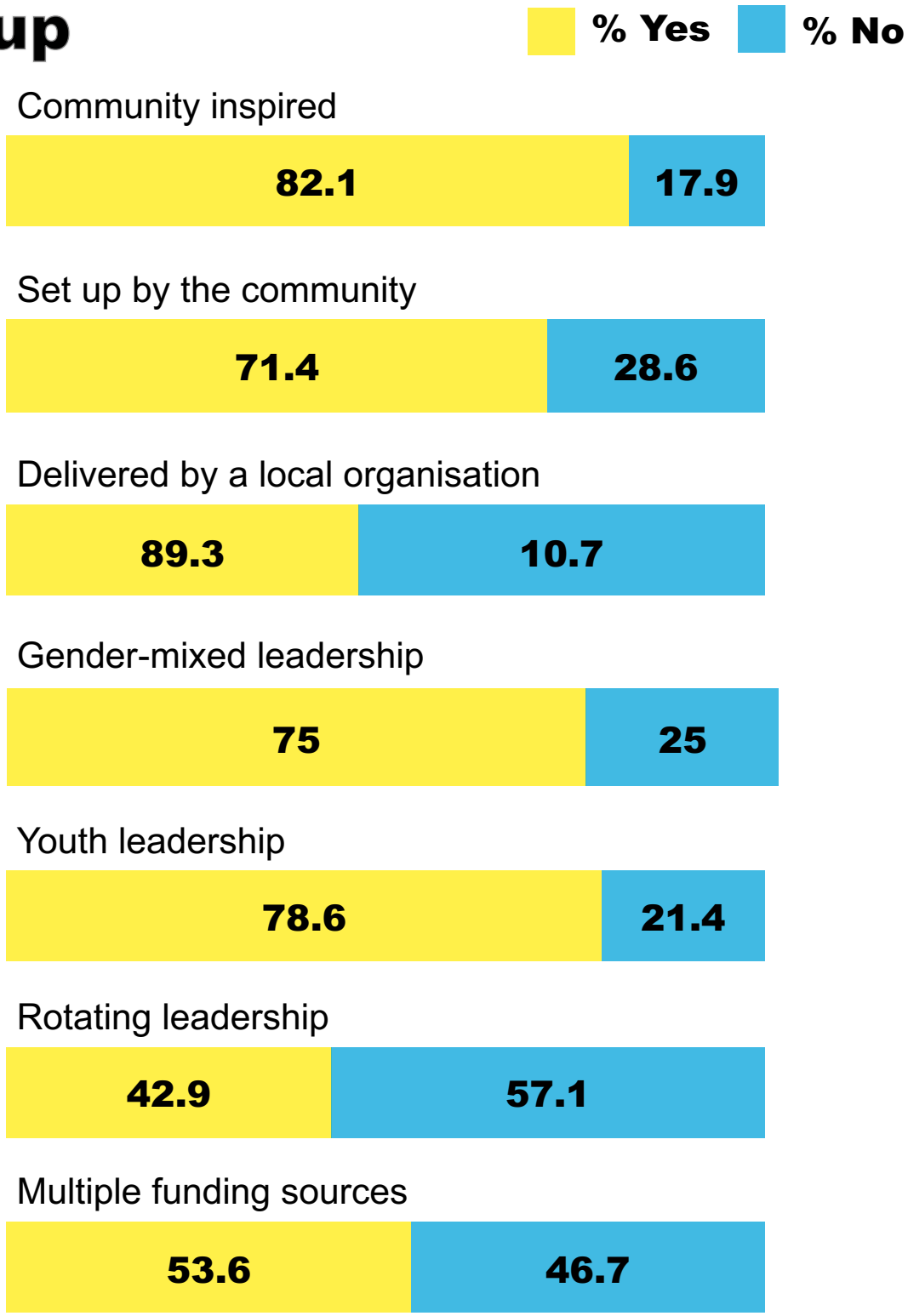
How do they work?

What is a CBO?

CBOs have been developed to support vulnerable children, especially those affected by HIV. Based in the local communities they are able to access more isolated families that may be inaccessible to health workers. CBOs allow for support to occur within the home and community, not just in clinics and hospitals.

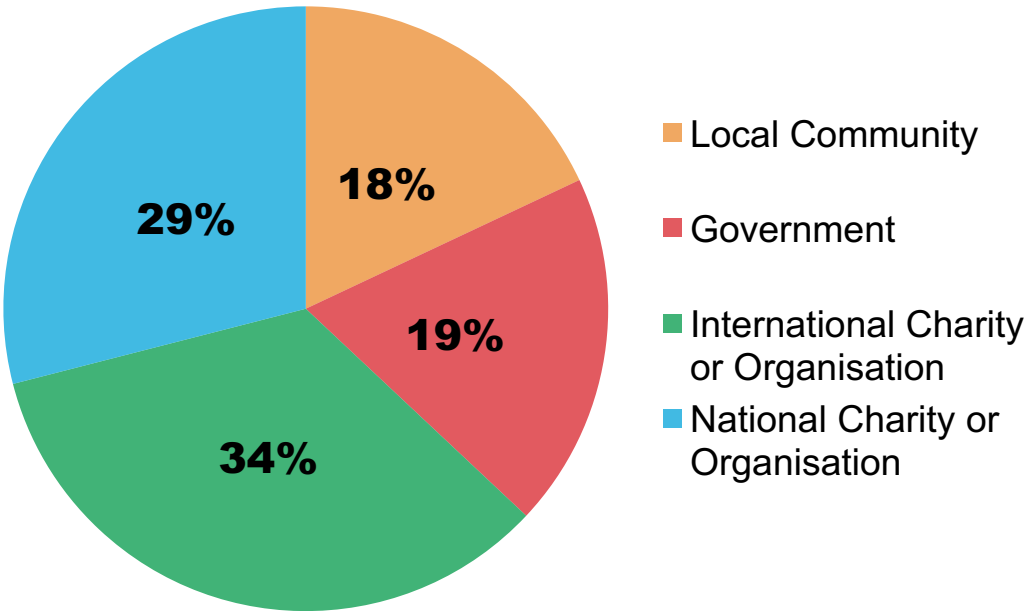
Typology of CBOs

Set up



Typology of CBOs

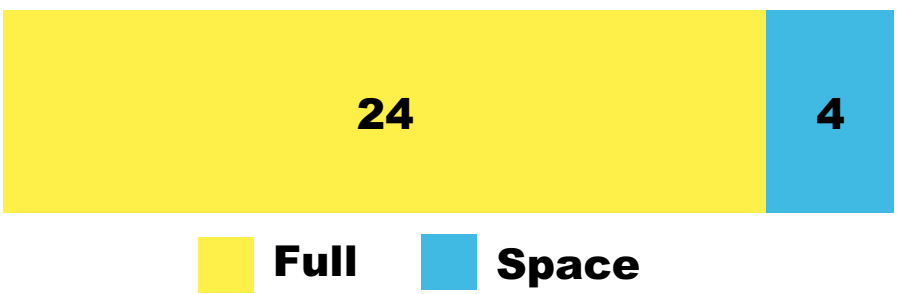
Funding Source



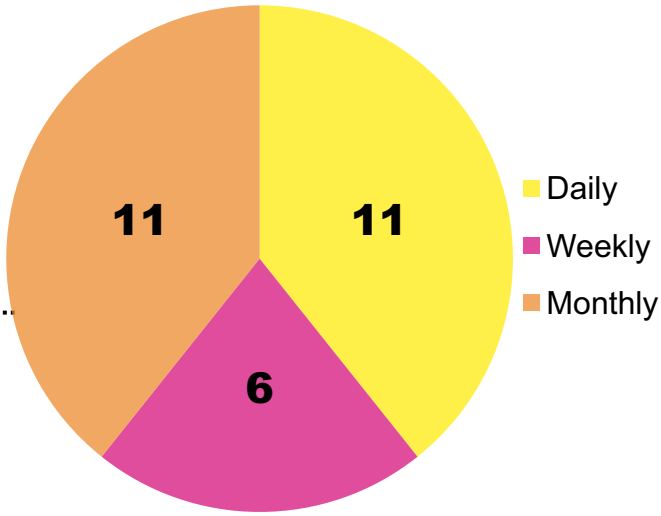
Capacity

Across the 28 CBOs selected for the Child Community Care study in South Africa and Malawi, there was variance in their capacity and the length and frequency of visits.

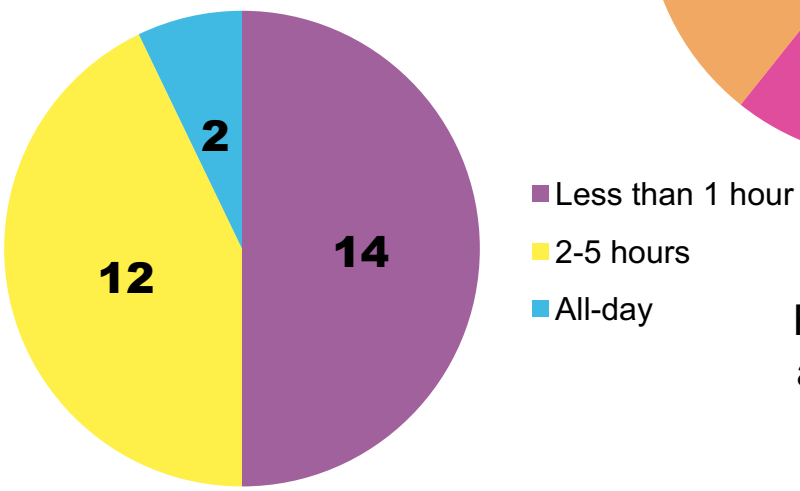
Capacity to take in more children



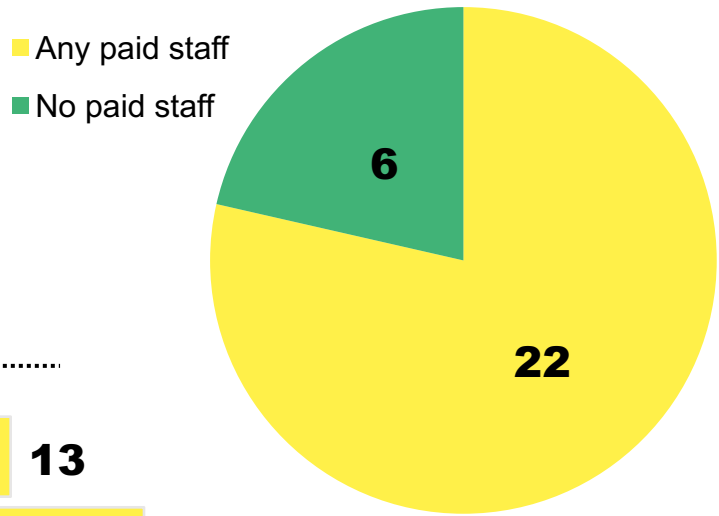
Frequency of visits made by CBOs to children



Duration of visits to children across CBOs

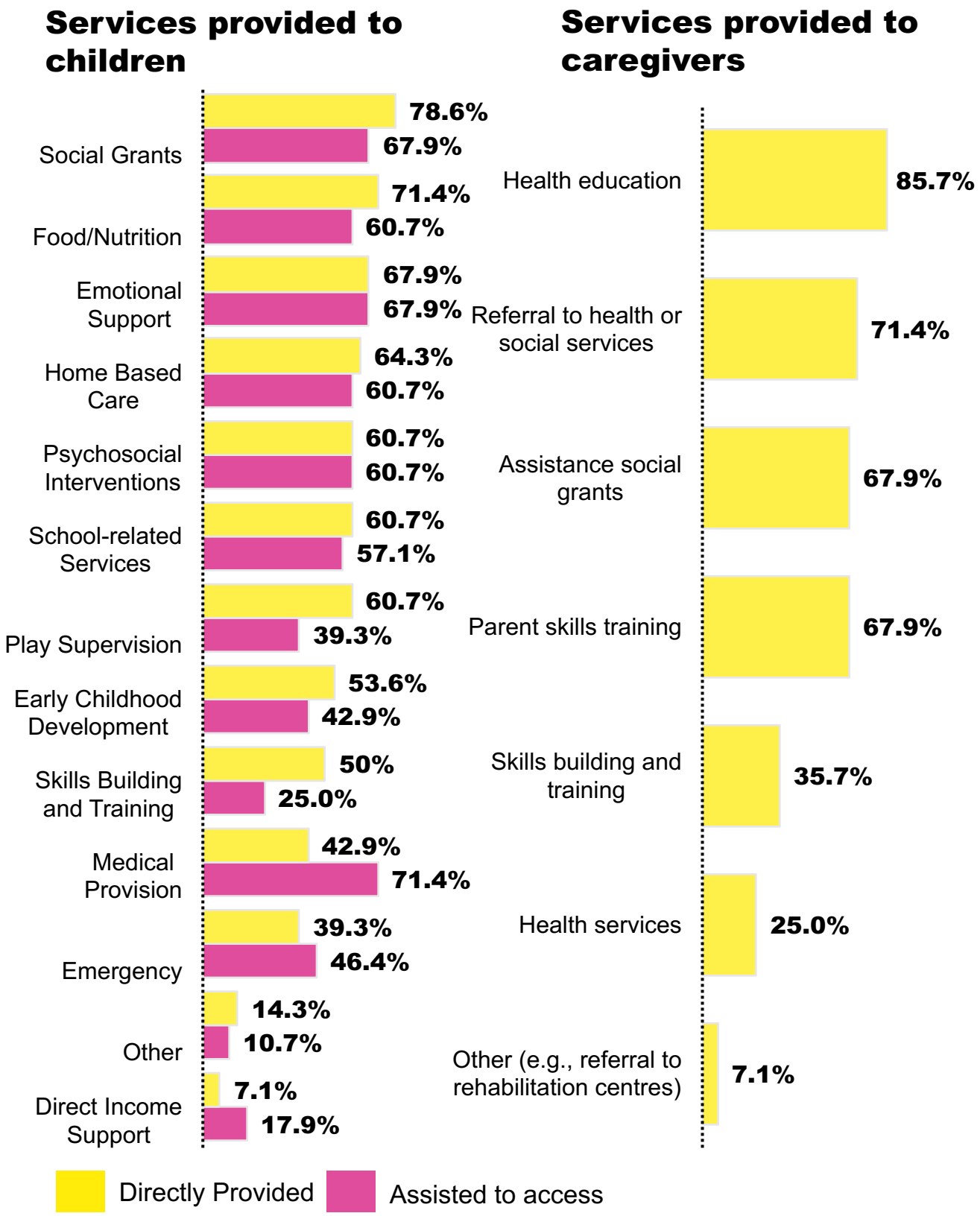


Frequency of CBOs with any paid or no paid staff members running the service



Frequency of different location visits at CBOs

Provisions


Services provided to children
Social Grants
78.6%
67.9%
Food/Nutrition
71.4%
60.7%
Emotional Support
67.9%
67.9%
Home Based Care
64.3%
60.7%
Psychosocial Interventions
60.7%
60.7%
School-related Services
60.7%
57.1%
Play Supervision
60.7%
39.3%
Early Childhood Development
53.6%
42.9%
Skills Building and Training
50%
25.0%
Medical Provision
42.9%
71.4%
Emergency
39.3%
46.4%
Other
14.3%
10.7%
Direct Income Support
7.1%
17.9%
Services provided to caregivers
Health education
85.7%
Referral to health or social services
71.4%
Assistance social grants
67.9%
Parent skills training
67.9%
Skills building and training
35.7%
Health services
25.0%
Other (e.g., referral to rehabilitation centres)
7.1%
Directly Provided
Assisted to access

ARE CBOS REACHING THE **MOST VULNERABLE** CHILDREN?

YES

Rationale

Ensuring that CBOs target the most vulnerable children has been highlighted as a priority. With the increasingly resource-constrained environment for funding it is important to confirm whether those most in need are able to access interventions and support. Therefore, children within the Child Community Care study, who had access to CBO support were compared to children within the Young Carers study, who did not have access to support to see if the most vulnerable were being reached.

CBO versus no CBO

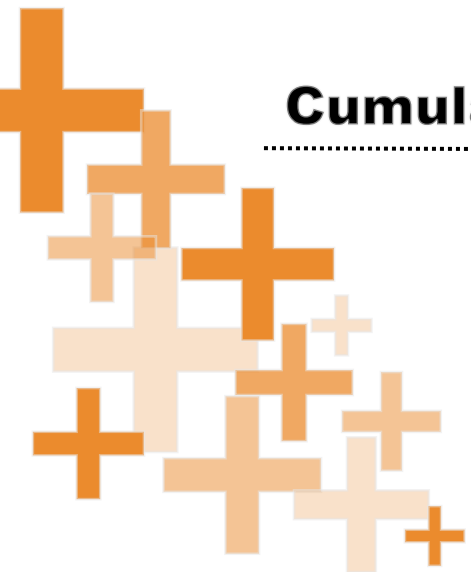
In comparison to the Young Carers study, children in the Child Community Care study, with access to at least one CBO, were found to be more often living in households without employment, were orphans, had seen or experienced community violence, cared for either other children or sick people and lived in larger households. However, fewer children attending CBOs were living in informal housing or with a HIV-positive caregiver.

What vulnerabilities affect CBO attendance?

In comparison to those without CBO contact, it does seem that children who are more vulnerable have greater access to support. Within children who had access to CBOs, some sociodemographic risks were better able to predict whether or not the child was attending the CBO and receiving subsequent support.

Children who were living in informal housing, living with at least one employed person, had a HIV-positive caregiver, were female or younger were less likely to be accessing CBO support that was available to them.

One the other hand, children who had at least one deceased parent, had seen someone being attacked, cared for younger children or lived with more people in one household were more likely to be accessing CBO services.



Cumulative Vulnerability

However, even though some risks were more associated with attending a CBO, it was found that the ***more*** risks experienced, the greater the chance that a child has attended a CBO. For every additional risk faced a child on average was around 2 times more likely to have attended a CBO compared to a children with less risks.

OUTCOMES OF CBOS:

DOES ATTENDING A CBO IMPROVE PSYCHOSOCIAL WELLBEING?

YES

Rationale

Until recently, research into how interventions impact the psychosocial wellbeing of children affected by HIV and AIDS has been lacking. Where research has lacked rigorous methodology or focus on the outcomes of an intervention, the Child Community Care study used both a comparison group (the Young Carers study) and a 12-15 month follow up to gain a better understanding of the benefits of the wealth of provisions and support that fall under the umbrella of CBO.

Baseline

Parental Praise

Weekly physical abuse

Weekly emotional abuse

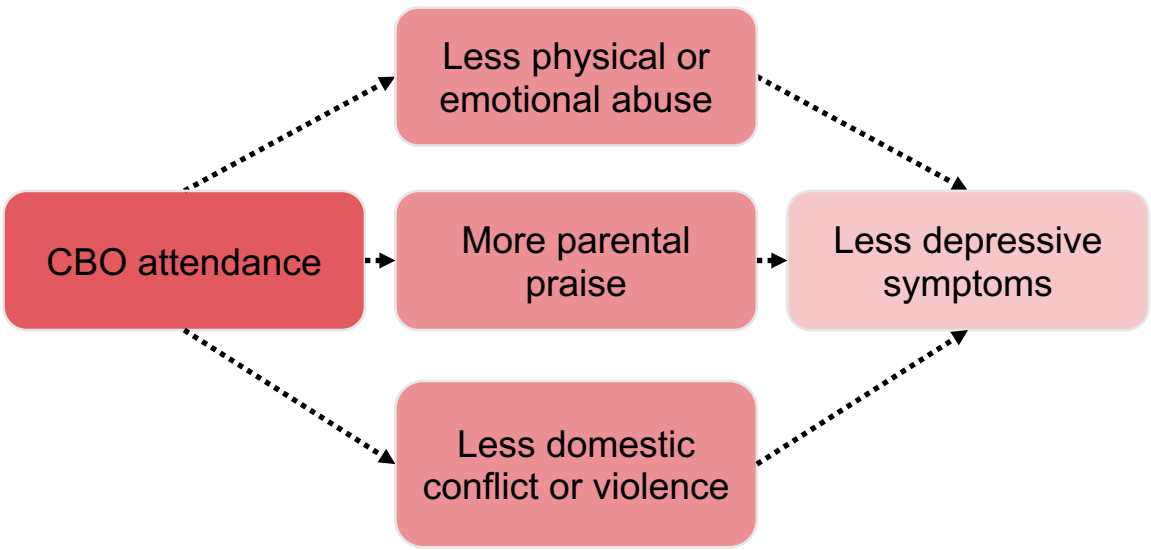
Weekly domestic conflict

Weekly domestic violence

Depressive symptoms

When children were first assessed within the Child Community Care study, it was found that children attending CBOs had reduced weekly physical and emotional abuse, domestic conflict and violence and less depressive symptoms than those who did not have access to a CBO. Both groups of children had similar levels of post-traumatic symptoms.

Further exploration of this finding highlighted that attending a CBO had a direct impact on the levels of abuse, parental praise and domestic conflict and violence. Changes in these factors was found to lead to a decrease in reported depressive symptoms.



Lasting effects over time

What effect does attending a CBO have on the psychosocial wellbeing of children, 12-15 months later?

Prosocial behaviour

Self-Esteem

From these findings it is possible that attending a CBO has effects on the psychosocial wellbeing of children. Twelve to fifteen months later children were still showing reduced levels of weekly physical and emotional abuse, weekly domestic conflict and violence and fewer depressive symptoms. In addition, children were also showing reduced levels of suicidal ideation, perceived stigma, peer problems and conduct problems and increased levels of prosocial behaviour in comparison with those who did not attend a CBO.

At follow-up it was also highlighted that attending a CBO still did not reduce or impact post-traumatic symptoms. Whereas, unlike at baseline, parental praise was not associated with attending a CBO after 12-15 months.

Weekly physical abuse

Weekly emotional abuse

Weekly domestic conflict

Weekly domestic violence

Depressive symptoms

Suicidal ideation

Perceived stigma

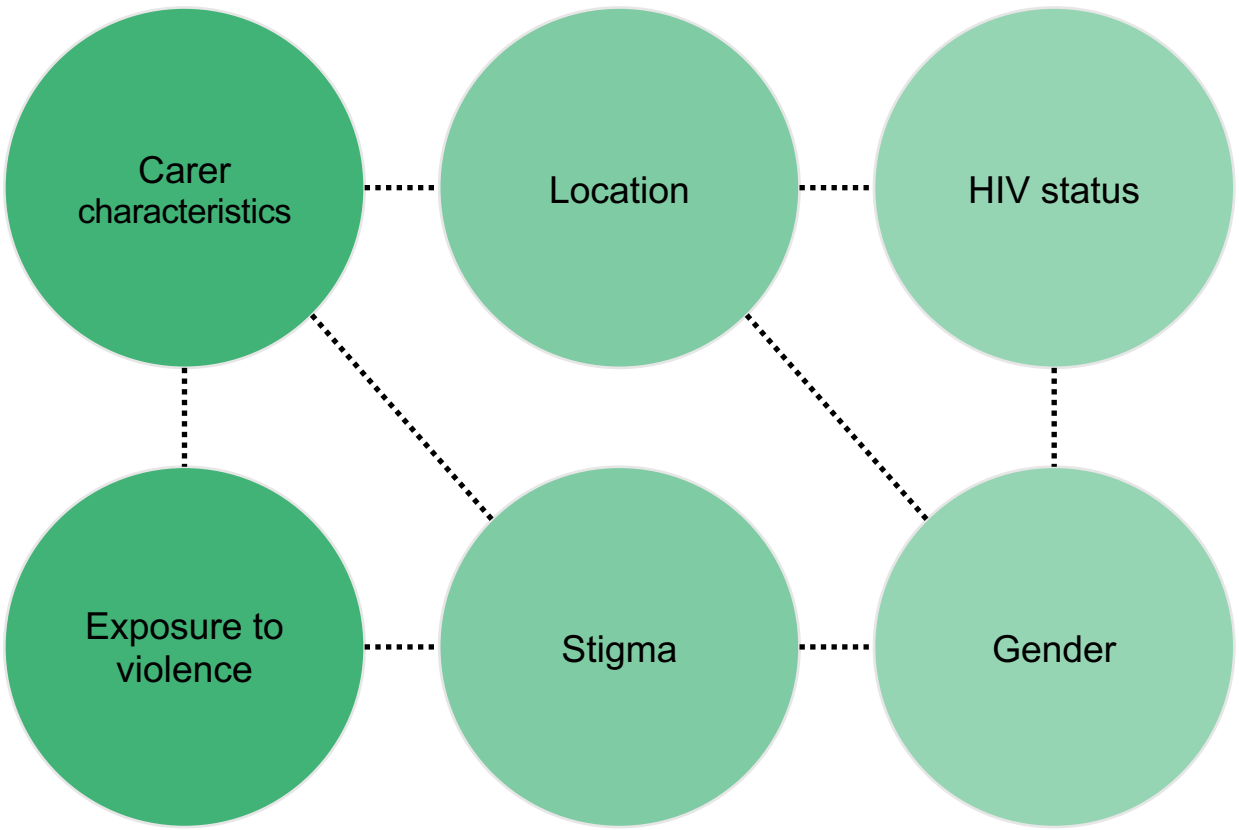
Peer problems

Conduct problems

WHAT **FACTORS** INFLUENCE THE EFFECTS OF A CBO?

Risk Factors

Research has began to emerge that suggests attending a CBO can benefit children affected by HIV and AIDS in a number of ways, for instance by improving their psychosocial wellbeing. However, there are a number of different factors that play a role and contribute to how beneficial a CBO may actually be to a child. It is important to take these factors into consideration and account for how they interact with attending a CBO. Below are a variety of factors that were additionally examined within the Child Community care study.



Carer Characteristics

Age

Caregiver demographics

35.4% aged 50 or over

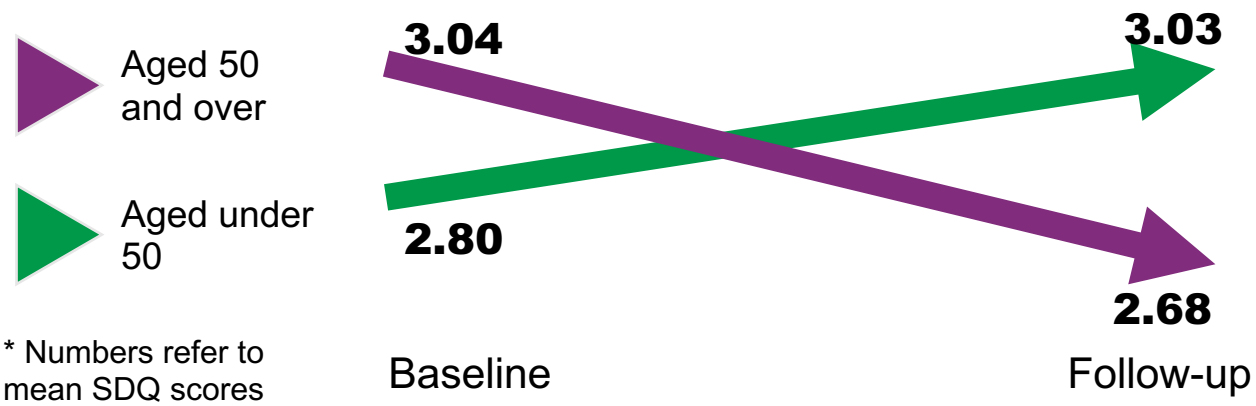
46.2% biological parent

29% grand-parent

95% female caregivers

Within the Child Community Care study, a high percentage of the primary caregivers within the sample were aged 50 and over. Yet there more mostly no differences in child outcomes depending on the age of the caregiver showing that older caregivers did as well as younger caregivers. Interestingly, children with caregivers aged > 50 initially had higher emotional and behavioural problems, however these declined when assessed 12-15 months later. Although children with caregivers under 50 started with lower problem behaviours, these increased at follow-up. Levels of problem behaviour scores were taken using the Strengths and Difficulties Questionnaire (SDQ) at both time-points.

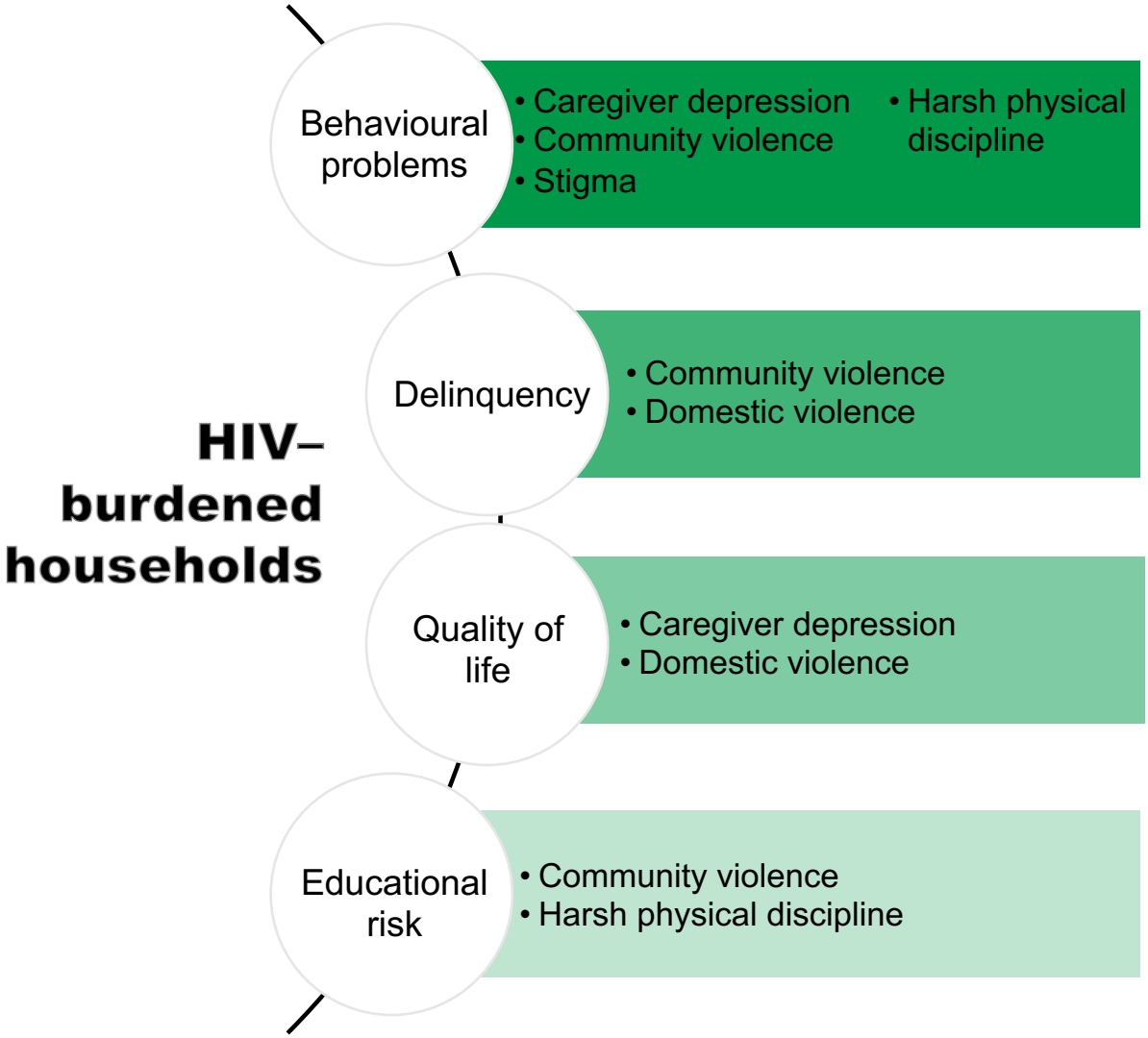
Problem behaviours in children



* Numbers refer to mean SDQ scores

Carer Characteristics

HIV Status



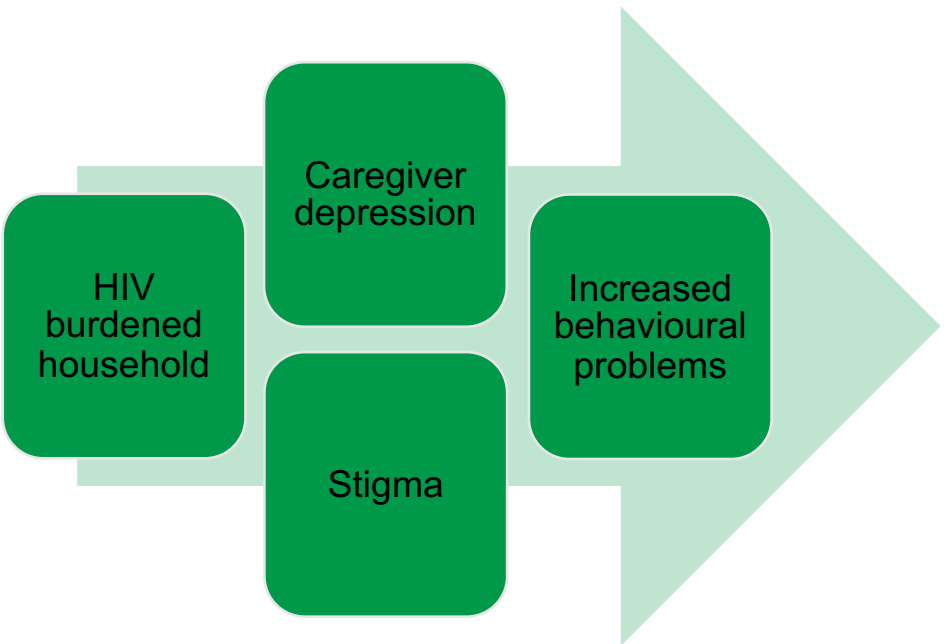
Coming from a HIV-burdened household has been associated with a number of negative outcomes. Children in these households are living with either an HIV-positive primary caregiver or with other HIV-positive household members. Children from these two HIV-burdened groups differed from those who came from households not affected by HIV (all above factors). Coming from an HIV-affected household did not directly affect behavioural problems, delinquency, quality of life and educational risk. However an indirect association with these four negative outcomes was found through the factors highlighted above.

Does carer and household HIV status interfere with the lasting benefits of attending a CBO?

YES

When first assessed, it was found that coming from an HIV burdened household was associated with a number of factors that lead to changes in behavioural problems, delinquency, quality of life and educational risks.

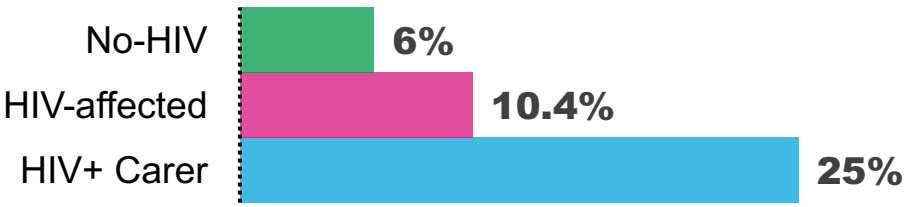
It has been shown that attending a CBO has a number of lasting effects and benefits for a child when assessed 12-15 months later. However, coming from an HIV burdened household has been found to interfere with this. Although it does not directly affect change in child outcomes, living with an HIV-positive carer or in an HIV-affected household has been found to affect behavioural problems in children indirectly through rates of caregiver depression and perceived stigma. This was present 12-15 months later, where children have had access to CBOs.



Does household HIV burden influence what CBO services are available?

YES

Medical services



Material services

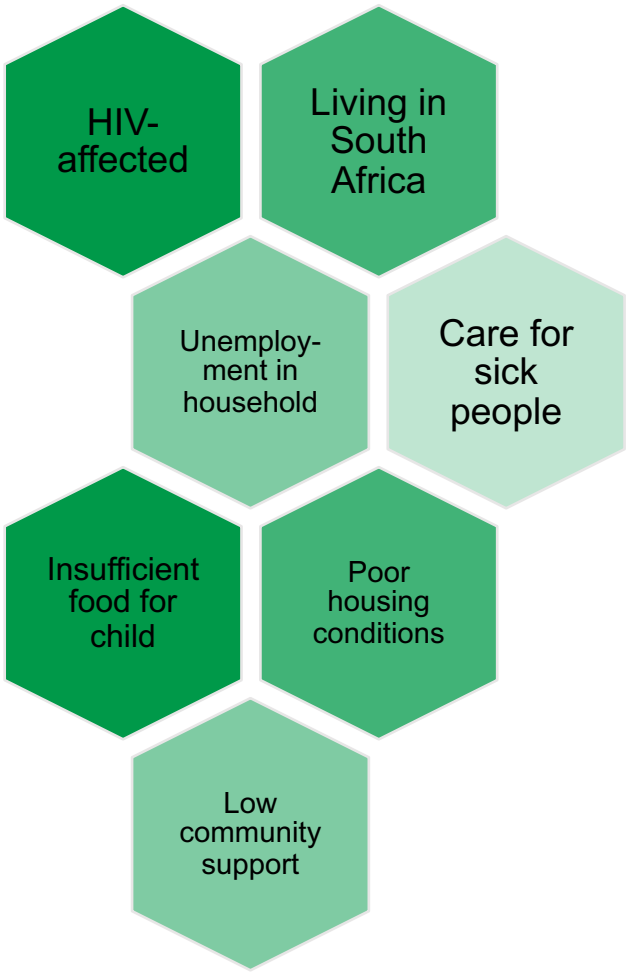
Educational services

Access to CBO services differed depending on the HIV status of the child's caregiver or household HIV burden. Although a number of CBO services were accessed, the three groups differed most in the amount of access they had to medical, material and educational services. Children with an HIV-positive carer had the most access to medical services, however had the least access to material and educational services. Whereas, those from a HIV-affected household had the most access to material and educational services.

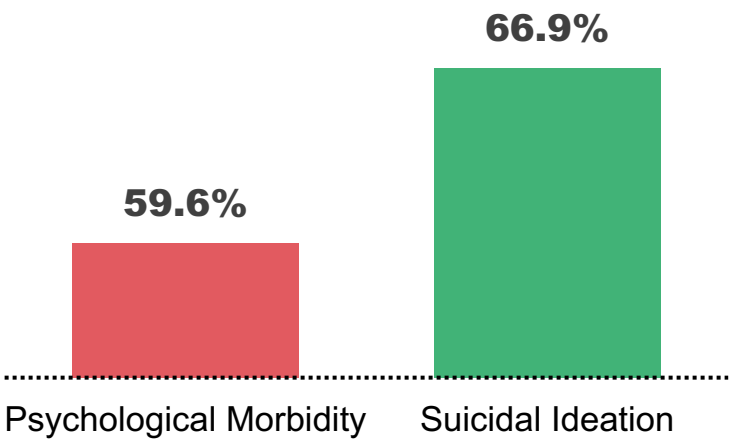
Carer Characteristics

Mental Health

The previous finding highlighted caregiver depression as a factor that consistently influenced a child's psychosocial wellbeing and development. When carer mental health and suicidal ideation was examined further (using the Shona Symptom Questionnaire and Patient Health Questionnaire, respectively). 28% of carers presented levels of psychological morbidity above the cut off level within the last week, and 12.2% recounted suicidal thoughts within the past two weeks. A number of factors were associated with increased reports of psychological morbidity and suicidal ideation.



Help-seeking



Only 59.6% of participants who reported psychological morbidity in the past week and 66.9% of those with suicidal ideation in the past two weeks sought help for mental or emotional distress.

Exposure to Violence

46.7% Of children witnessed **domestic violence** between adults in their home.

42.5% Of children that were exposed to violence within their **community**.

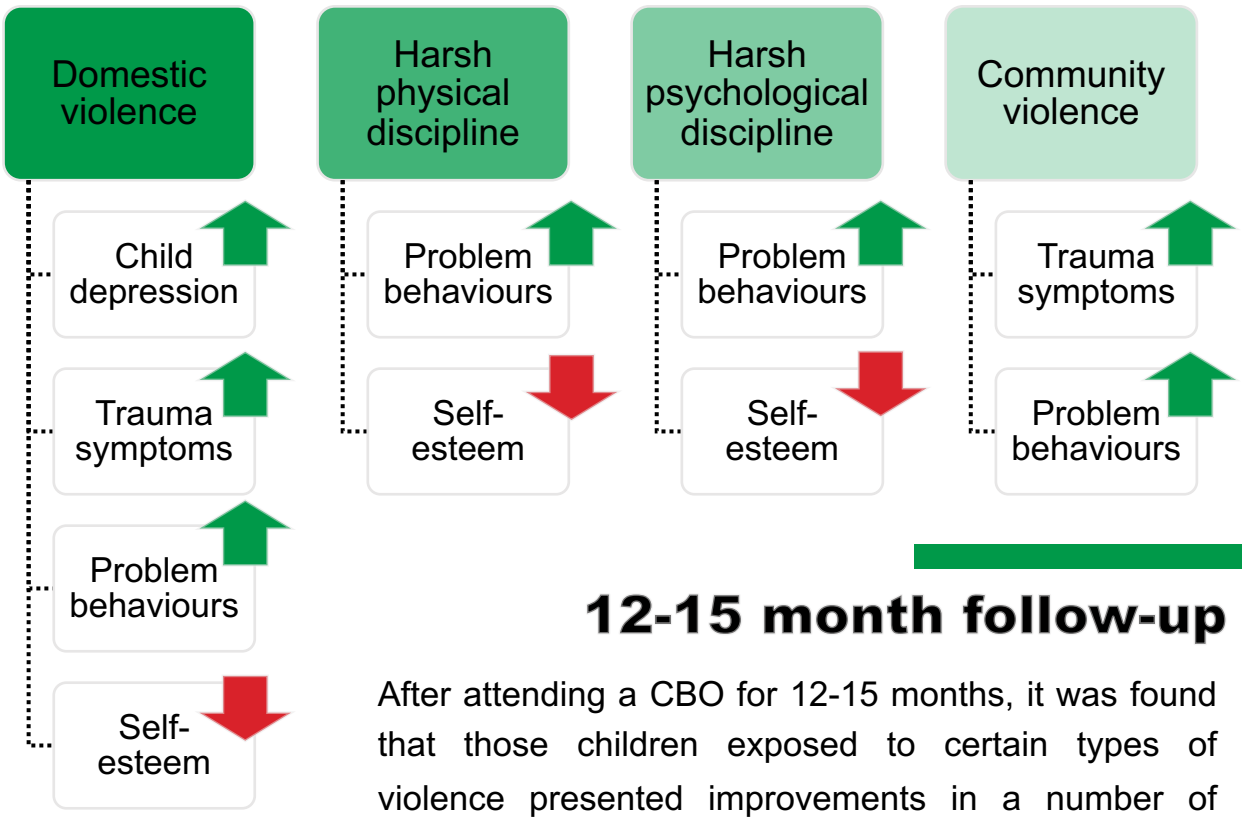
47.8% Of children experienced harsh physical discipline where they were hit with an implement or to the head or face.

45.4% Of children experienced harsh psychological punishment where they were threatened or called names.

Does exposure to violence affect a child's psychological wellbeing?

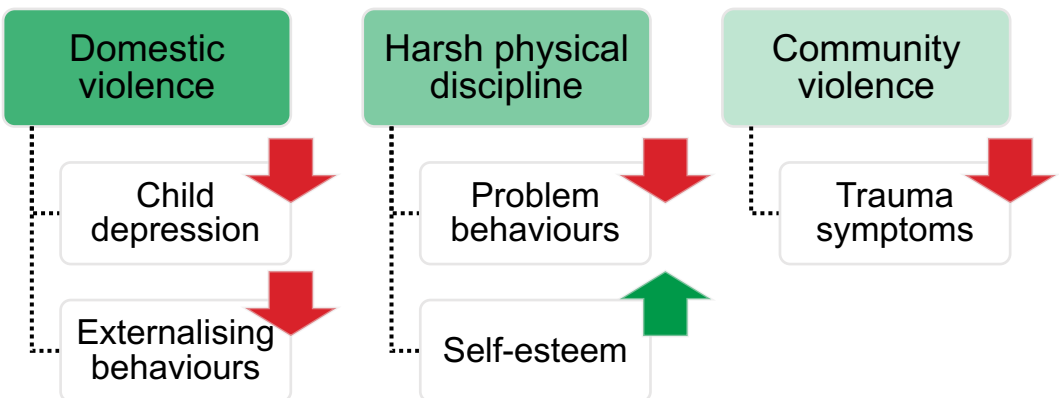
YES

At baseline it was found that exposure to violence impacted children's psychological wellbeing in a number of ways, from emotional and behavioural problems through to depression.



12-15 month follow-up

After attending a CBO for 12-15 months, it was found that those children exposed to certain types of violence presented improvements in a number of areas linked to their psychological wellbeing.



Does exposure to violence affect a child's education?

YES

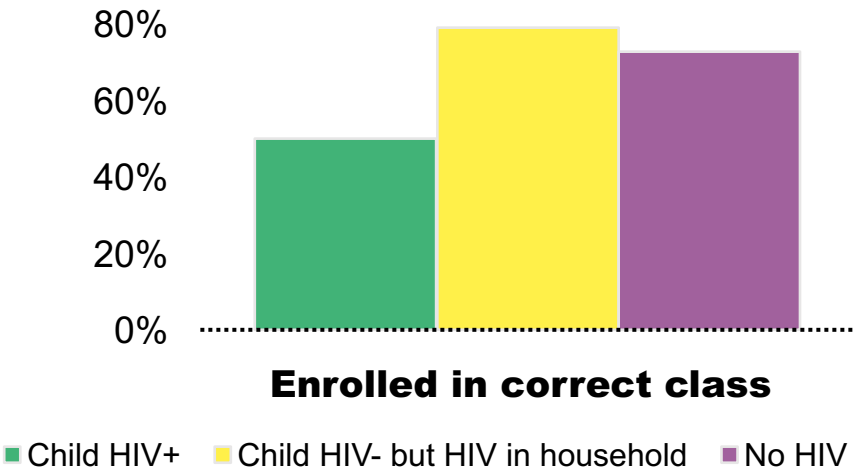
School Enrolment

At baseline, levels of violence that children experienced was not associated with whether a child was enrolled to study at school. However, when rates of enrolment were examined 12-15 months later, children who experienced harsh psychological punishment were ***10 times*** less likely to be enrolled to study at school.

10x less likely

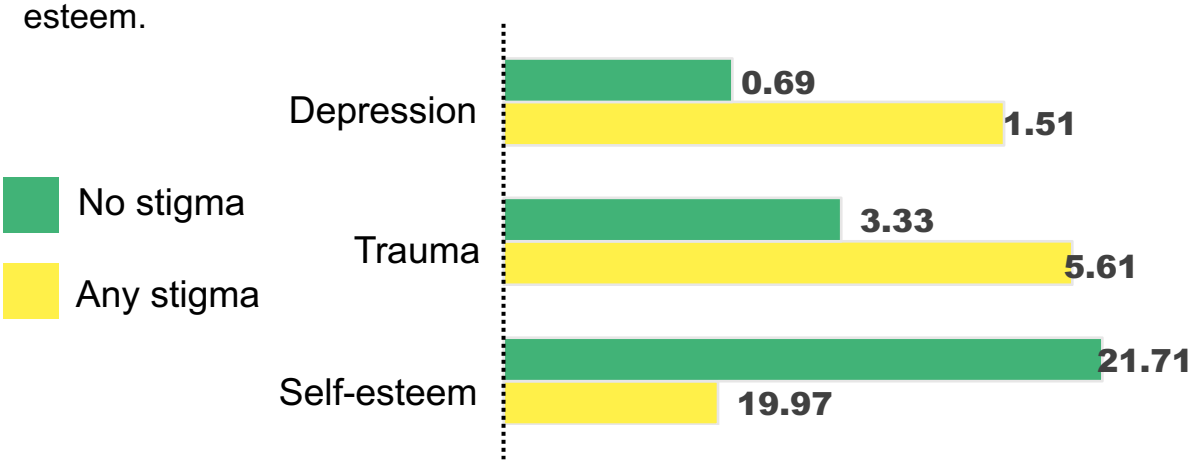
School Progress

School progress was assessed by children being in the correct class for their age group. At baseline, children who were HIV-positive were much less likely to be in the correct class at school. Children who had experienced harsh physical discipline were also at less likely to be in the correct class. When children were examined at follow-up, it was found that violence only impacted HIV-positive children. Where harsh physical discipline experienced at baseline was found to negatively impact grade progression.



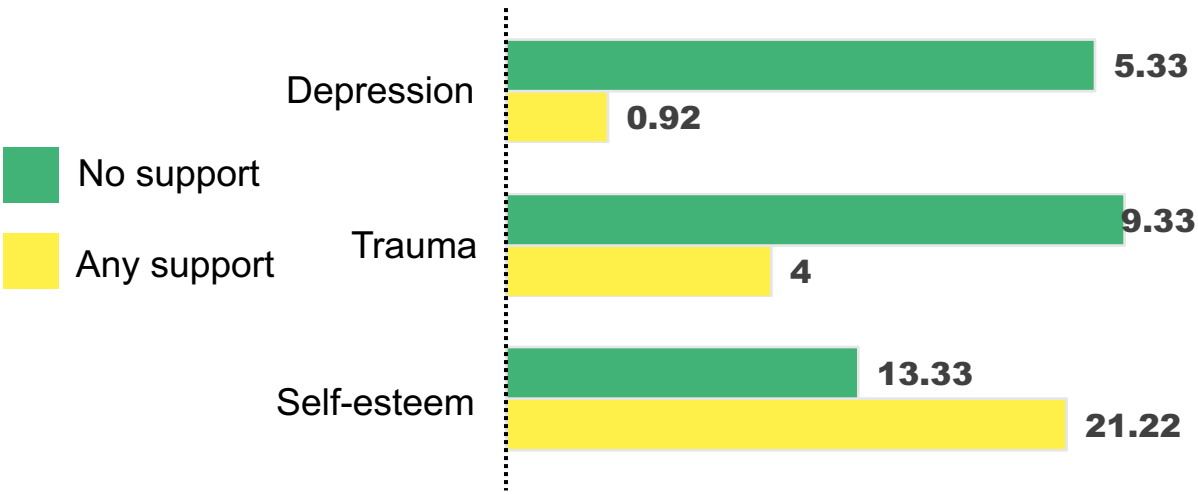
Stigma

Until this point, the study of stigma has mainly focused on the impact it has on adults. However, it has been important to address this issue with children. It was found that stigma affects the psychosocial wellbeing of children. Children who were faced with more stigma were at greater risk of heightened levels of depression and trauma and lower levels of self-esteem.



Stigma & support

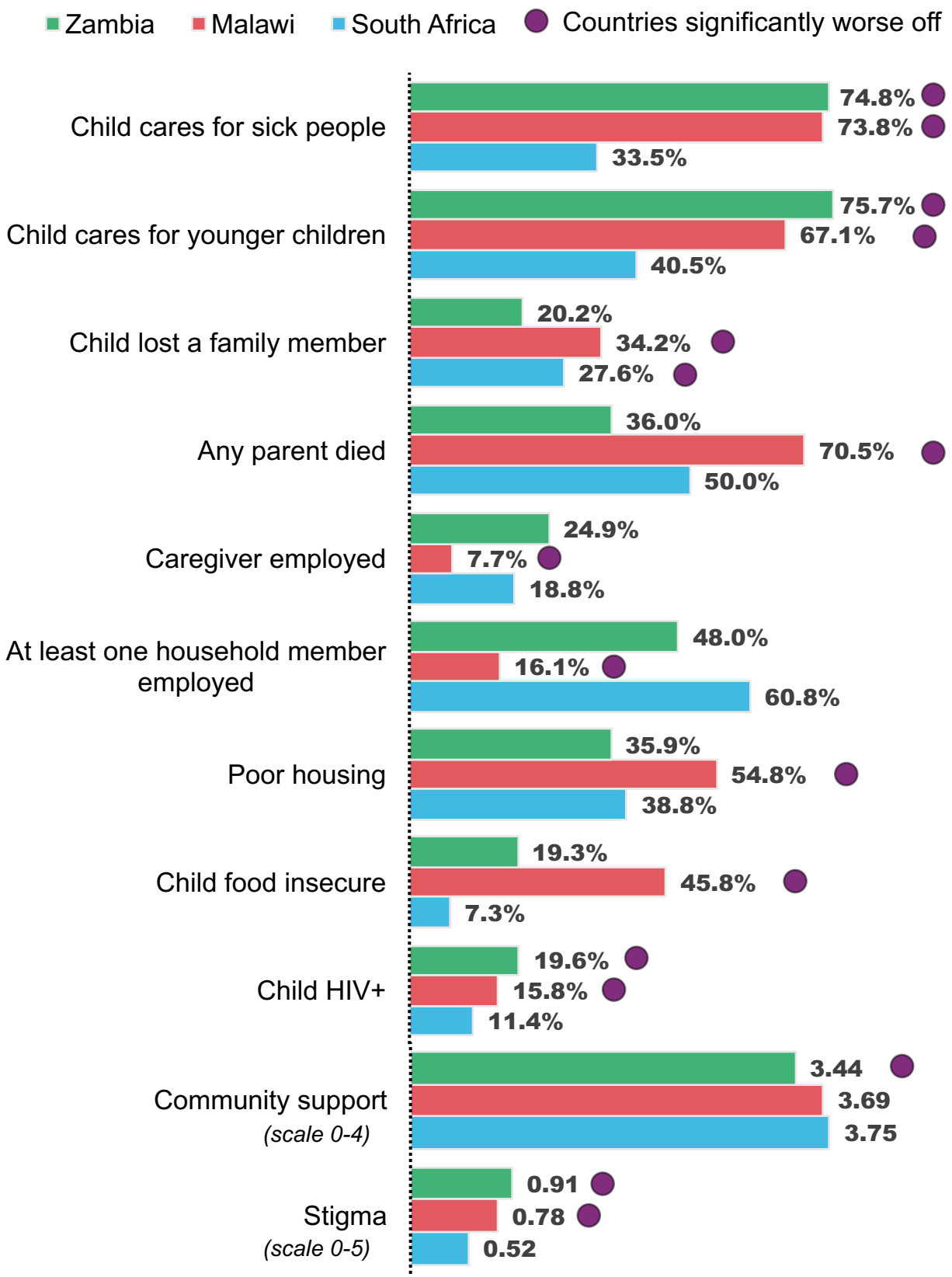
As previously highlighted, support received by the community and CBOs plays an important role in improving the psychosocial wellbeing of these children. The negative impact of stigma can be alleviated will any support from the community. Children without access to support presented further elevated rates of depression, trauma and lowered self-esteem.

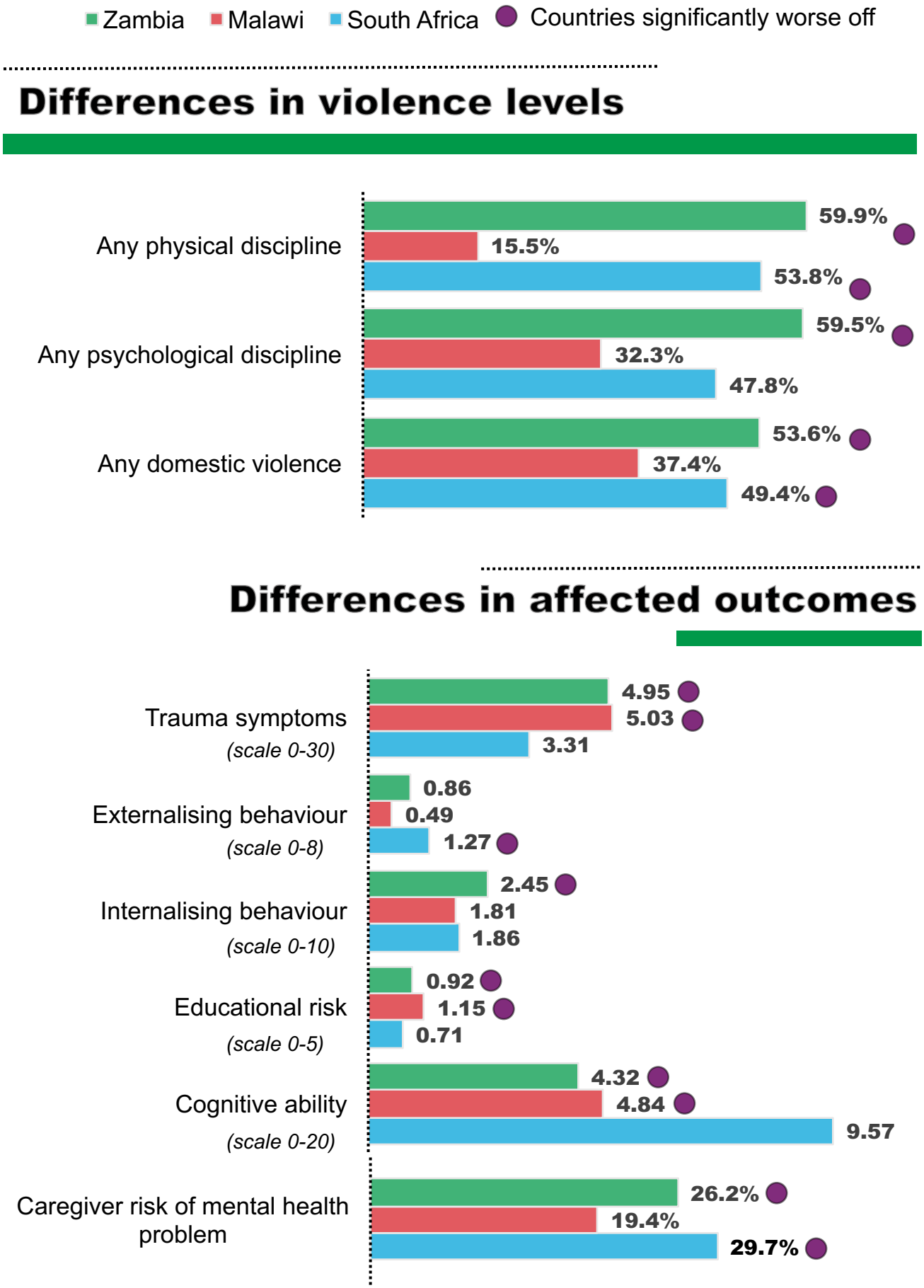


Location Differences

Three countries were examined within the Child Community Care study, South Africa, Malawi and Zambia. These countries differed on a number of factors. In general, it appears as though children in Malawi and Zambia are worse off than children in South Africa. This may impact how a CBO and support benefits an individual. Therefore, the country of the child needs to be taken into account when evaluating the impact of support.

Demographic differences



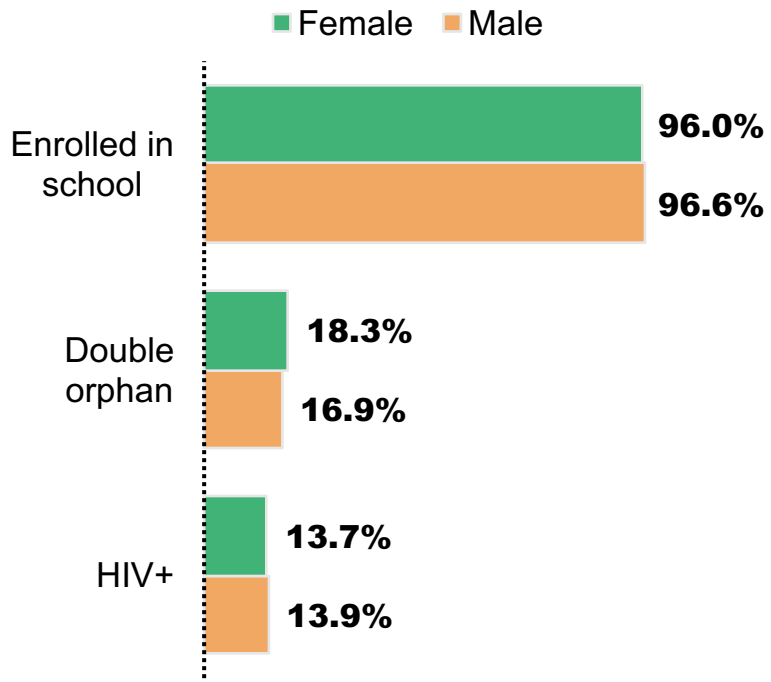

Zambia
Malawi
South Africa
Countries significantly worse off
Differences in violence levels
Any physical discipline
59.9%
15.5%
53.8%
Any psychological discipline
59.5%
32.3%
47.8%
Any domestic violence
53.6%
37.4%
49.4%
Differences in affected outcomes
Trauma symptoms
(scale 0-30)
4.95
5.03
3.31
Externalising behaviour
(scale 0-8)
0.86
0.49
1.27
Internalising behaviour
(scale 0-10)
2.45
1.81
1.86
Educational risk
(scale 0-5)
0.92
1.15
0.71
Cognitive ability
(scale 0-20)
4.32
4.84
9.57
Caregiver risk of mental health problem
26.2%
19.4%
29.7%

Gender Differences

A great deal of research highlights that gender is an important factor in child development. Therefore, the Child Community Care study examined the effect of gender on the development of children attending CBOs, and whether CBO attendance was associated with gender over time.

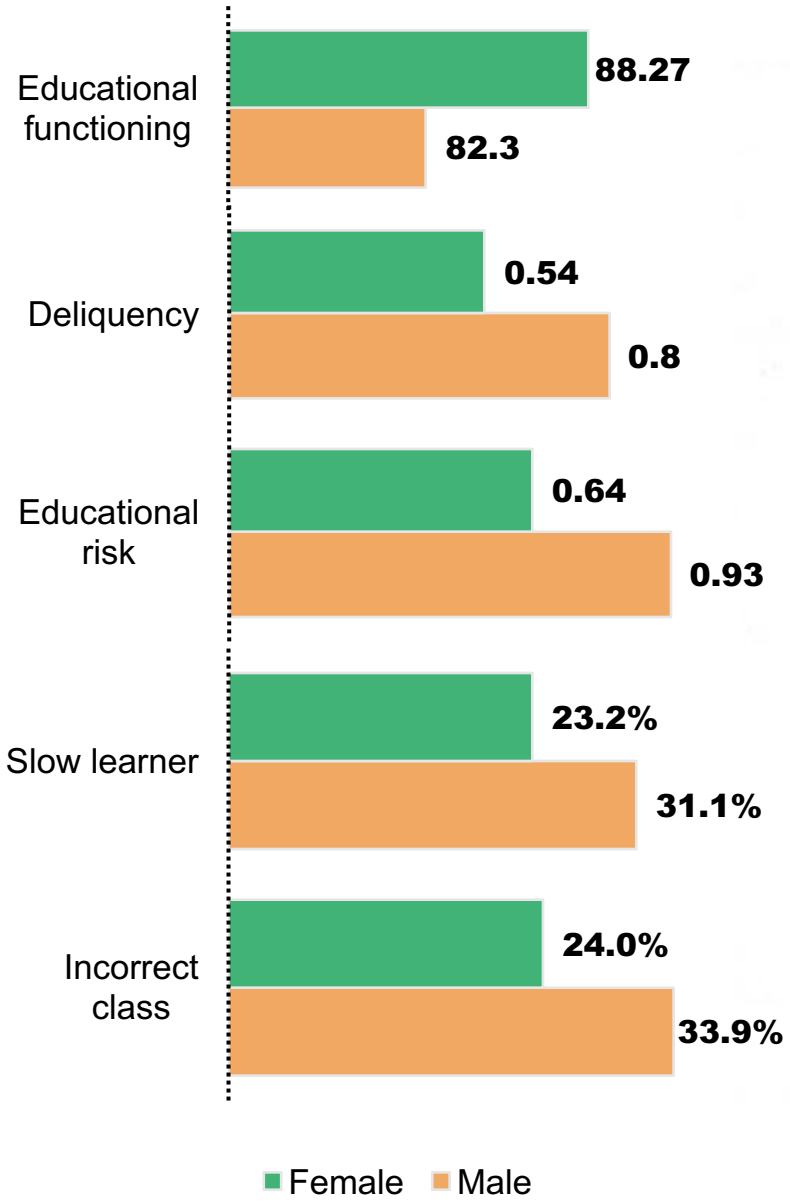
476 boys

503 girls



In terms of demographic information, both boys and girls were very similar with limited to no differences between qualities such as HIV-status and school enrolment. However, at baseline, boys and girls were quite different in three core areas; their ***exposure to violence,*** the outcomes of their ***education*** and their ***behavioural problems***.

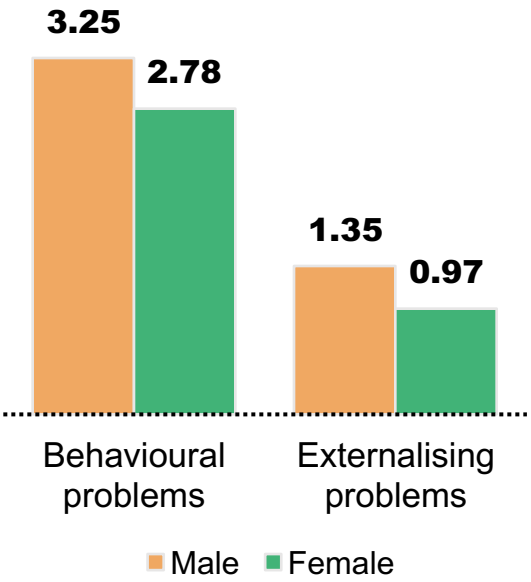
Educational outcomes

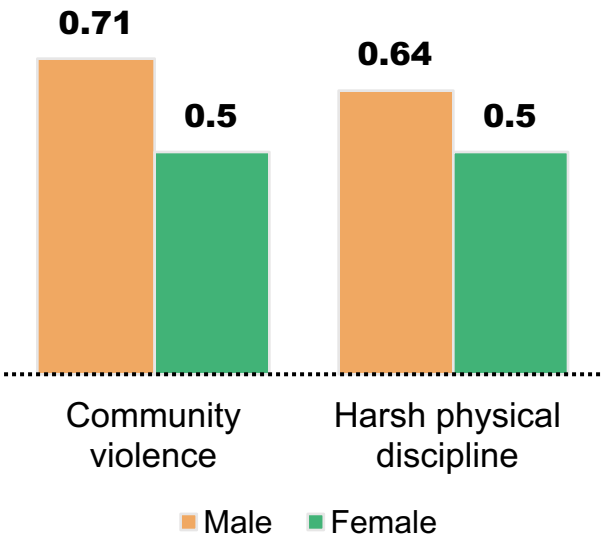


At baseline, boys and girls differed in a number of areas associated with their education. Although previous research has indicated that girls in sub-Saharan Africa tend to have less access to education than boys, they have been shown to have increased levels of educational functioning. Whereas, boys have shown higher levels of delinquency and educational risk. Alongside that, in our study more boys than girls were also found to be slower learners and in the incorrect class for their age group at school.

Behavioural problems

Boys and girls also differed in the amount of behavioural problems that they displayed. In general, boys tended to have more behavioural problems that girls. They also had higher levels of externalising problem behaviours.

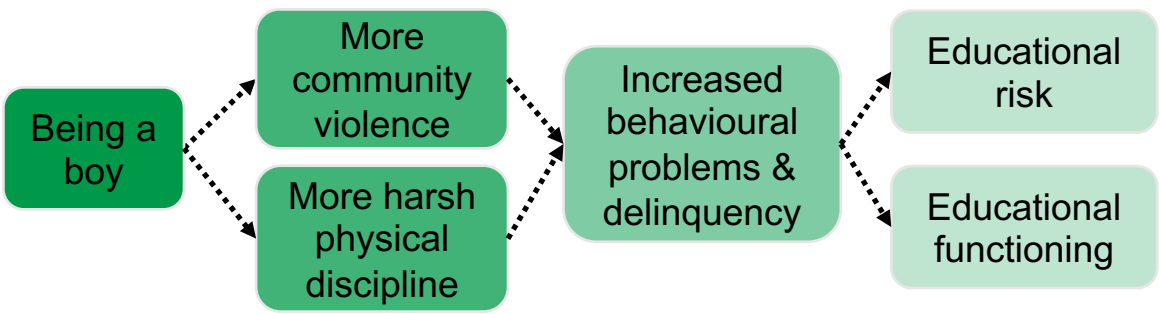


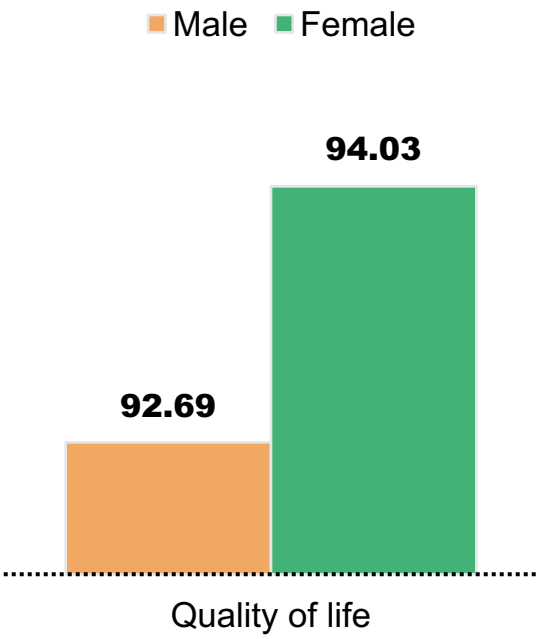


Violence

Finally, gender was also a factor with levels of violence experienced. Boys experience more community violence and harsh physical discipline within the home than girls.

When the differences between boys and girls were explored in greater detail it was found that a number of the differences were interlinked. It was highlighted that, in boys, both increased community violence and harsh physical discipline indicates increased behavioural problems and delinquency, which in turn decreases educational functioning and increases educational risk.



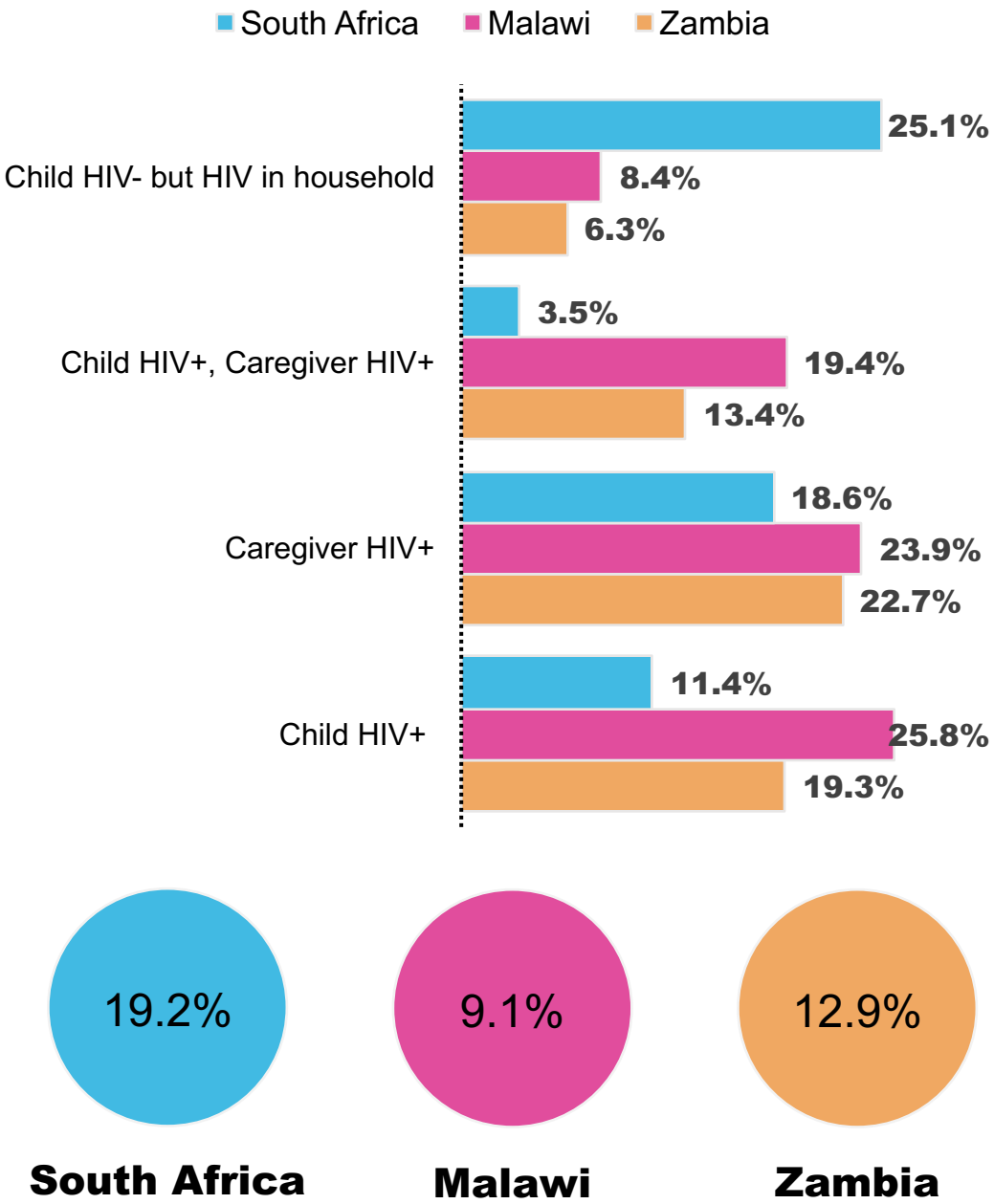


The children were reassessed 12-15 months later. All the differences surrounding educational outcomes, exposure to violence and behavioural problems that were found at baseline were all still significantly different at follow-up. Where girls presented better educational outcomes, less exposure to violence and less behavioural problems. In addition boys also showed a decline in quality of life scores compared to girls.

Where previous research has emphasised how there are imbalances in services and education available to girls, programmes and support addressing child development have been aimed at girls. However, the Child Community Care study highlights that focusing provisions on girls may leave the **boys overlooked**. They have shown more negative outcomes across a number of measures, so it is therefore important to focus on more equal approaches to child development. **Do not forget the boys!**

HIV INFECTION: HOW DOES IT AFFECT THE LANDSCAPE?

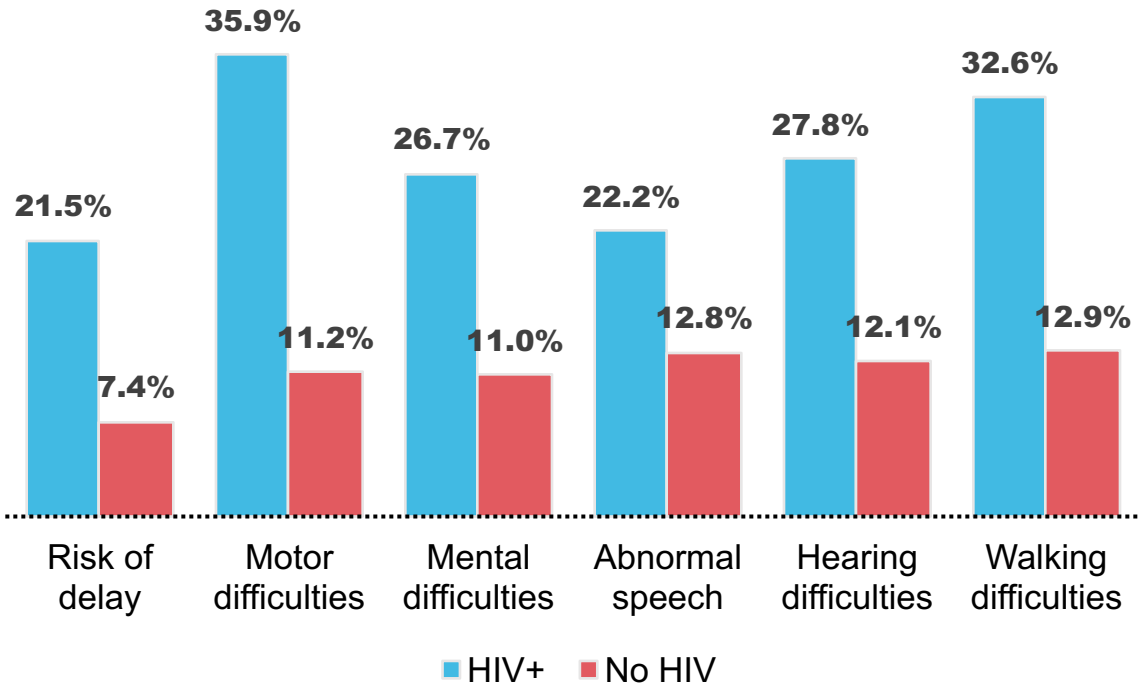
HIV prevalence



Across the three countries examined within the Child Community Care study there was some variation in prevalence rates of HIV. For instance, there was a much greater number of children in South Africa who were HIV-negative but living in a HIV-affected household. Here child and caregiver HIV status are presented alongside the HIV prevalence rates for those aged 15-49 in South Africa, Malawi and Zambia (as presented by UNAIDS, 2015).

Developmental outcomes

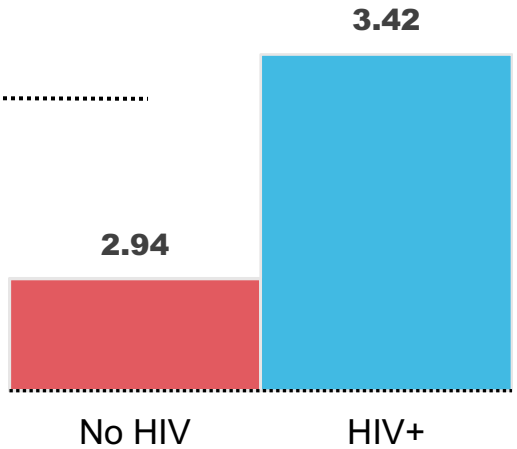
Developmental delay



Across a number of tests, children aged 4-13 who were HIV-positive were more often found to display levels of developmental delay that was not present in children who did not have HIV. These children in general were at greater risk of having a developmental disability and presented more severe developmental delays. Developmental differences between those who are and are not HIV-positive may lead to differences in the impact and benefits of receiving support from local CBOs.

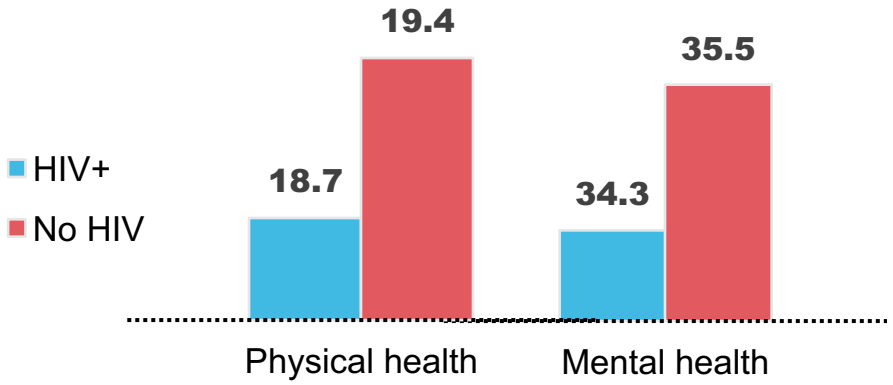
Problem behaviours

HIV-positive children were also found to have developed a significantly greater number of problem behaviours in comparison to children who did not have HIV.

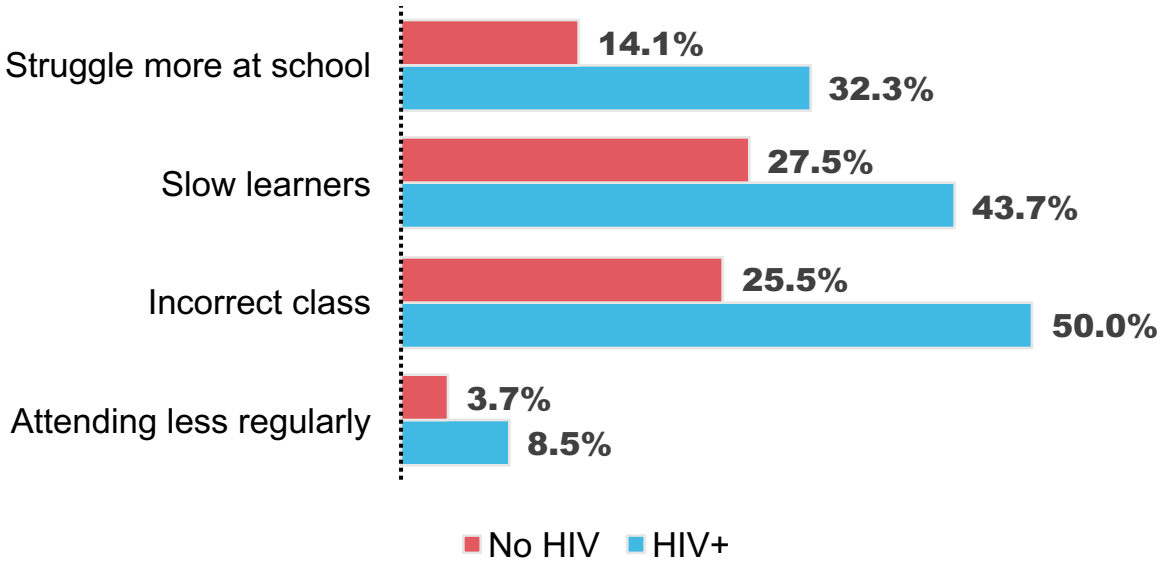


Health-related quality of life

Children with a positive HIV status were also found to have lower scores on measures assessing their quality of life. Having HIV was associated with both lower physical and mental health scores.



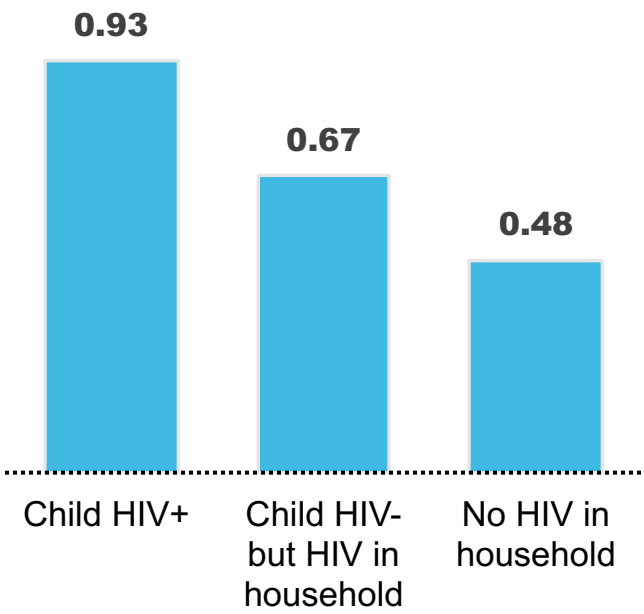
Development & education



HIV status has also been found to impact upon how a child develops and progresses through school and education. Within the Child Community Care study, HIV-positive children were found to struggle more at school, attend classes less regularly and were generally slower learners. They were also more often found in lower class than what was usual for their age group.

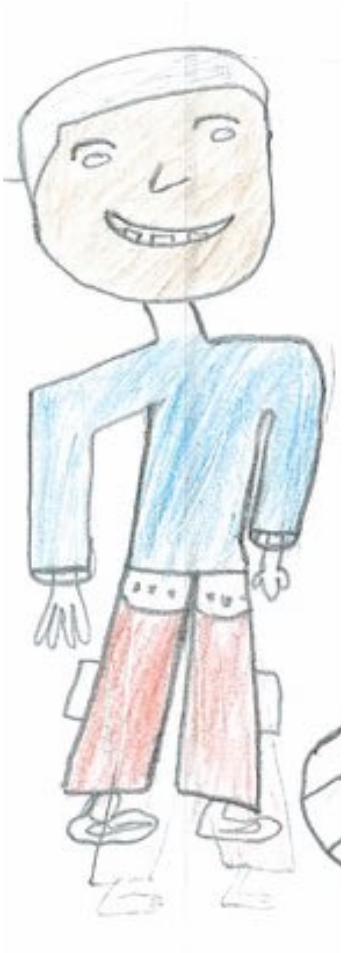
HIV & Stigma

Having HIV comes with a great deal of negative stigma. This is something that is found time and time again in adults dealing with HIV. The Child Community Care study also found that HIV-positive children perceived themselves as the most stigmatised, followed by those living without HIV but in an HIV-affected household.

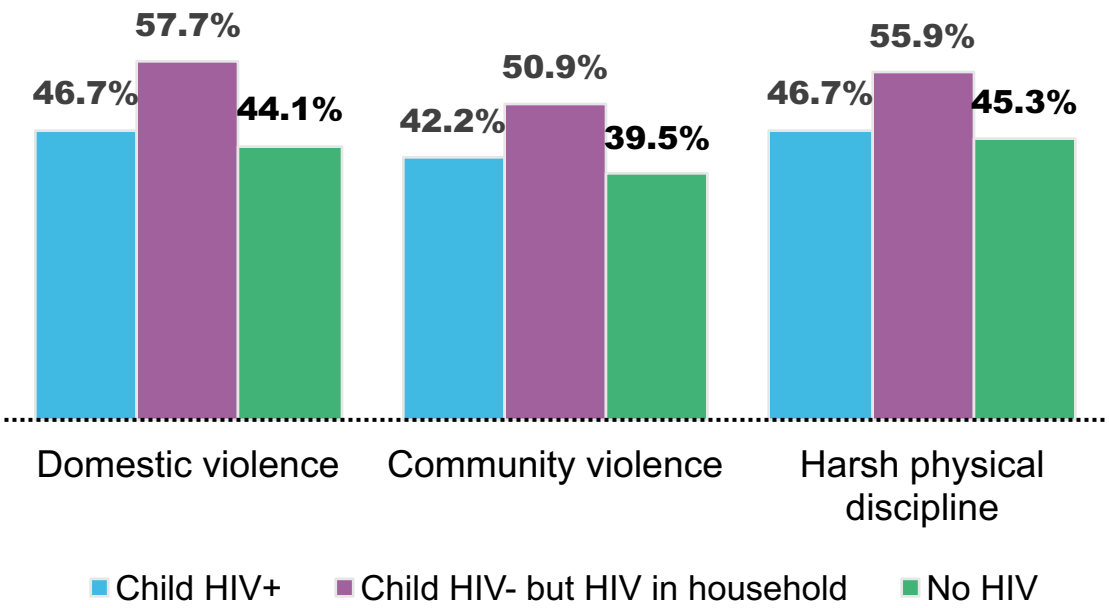


HIV & Violence

As previously highlighted, a high percentage of children within the Child Community Care study have experienced violence in one way or another, whether it was witnessing domestic violence between adults in the home, violence within the community or whether they'd been a victim to either harsh physical or psychological discipline.

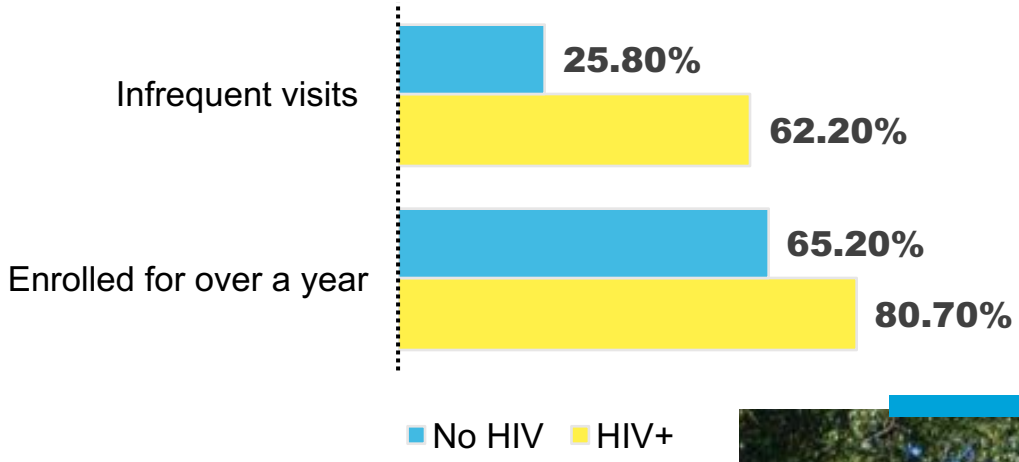


Within this study it was found that the HIV status of the child played a role in the level of violence experienced. Children who were not HIV-positive but lived with HIV in their household reported witnessing the most domestic and community violence. They also reported the highest levels of harsh physical discipline where they were either hit on the head or face or with an implement. This was followed by HIV-positive children then children not affected by HIV.



Does a child's HIV status affect their access to CBOs?

YES



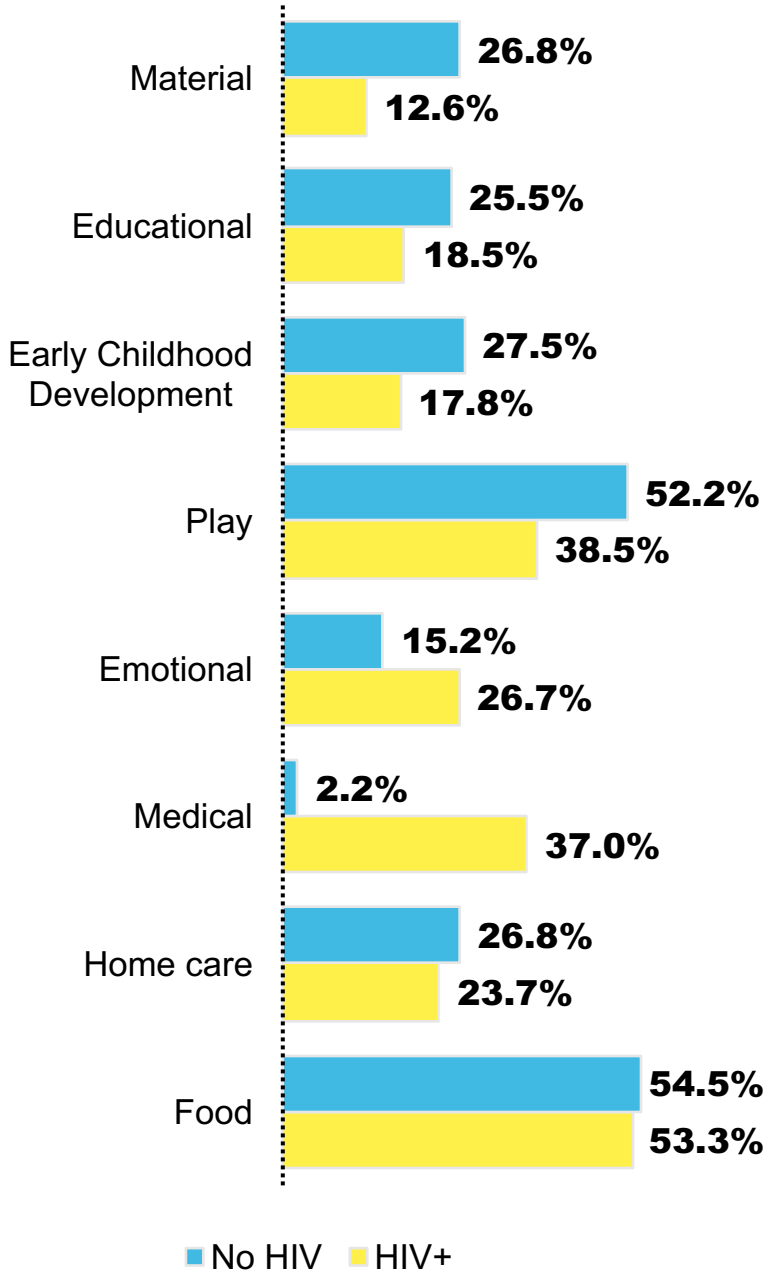
Contact with CBOs

A child's HIV status has been found to impact their wellbeing in a number of ways, from the amount of violence experienced to their psychological and intellectual development. HIV status has also shown differences in how children access and use CBOs. Firstly, it was found that a greater number of children who were HIV positive were enrolled within CBO services for over a year.

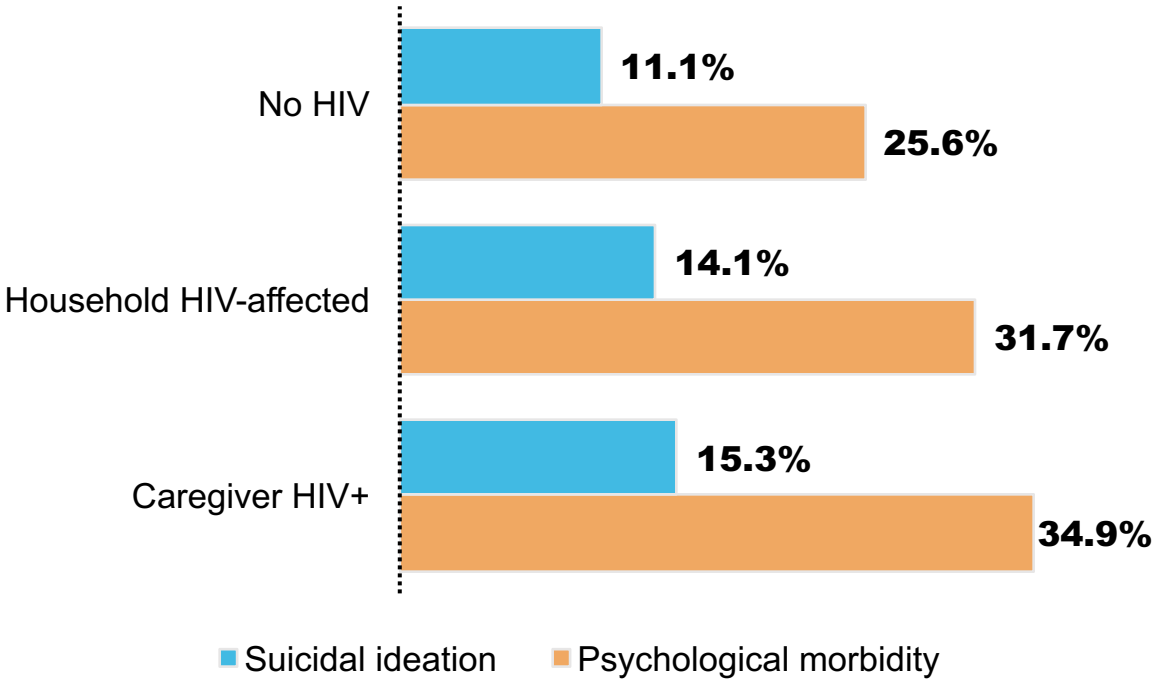
Secondly, these children were receiving much less frequent visits than children who did not have HIV. 62.2% of HIV positive children were visited only monthly or less often.

CBO provisions

It has also been found that depending on their HIV status, children have had access to different types of CBO provisions. Children with HIV had much greater access to medical and psychosocial, emotional interventions. However, they had much less access to educational support alongside play groups with other children and early childhood intervention groups.

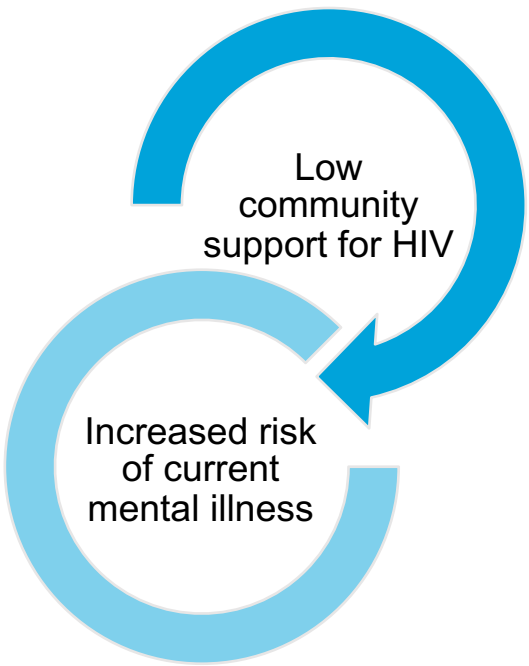


Carer HIV status



The HIV status of a child's carer is also an important factor that needs to be addressed. HIV-positive carers and carers living in HIV-affected household showed heightened levels of psychological morbidity and suicidal ideation in comparison to those who were not affected by HIV.

In addition, carers who reported low levels of support from their community for HIV were more often found to have a current diagnosis of a mental health problem.

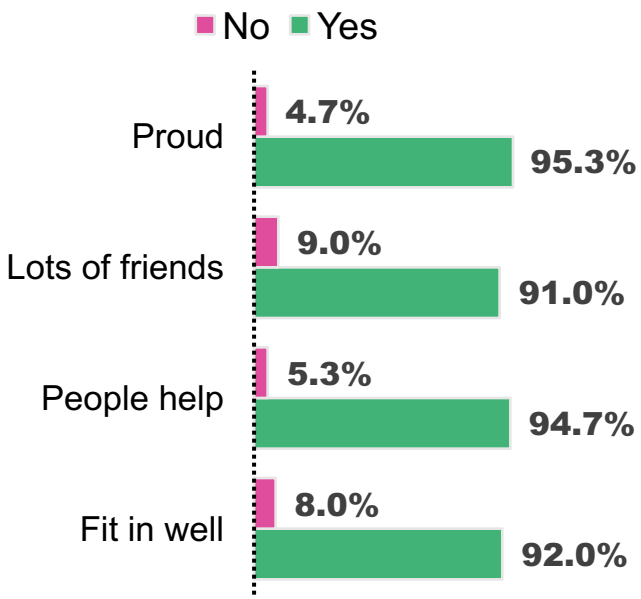


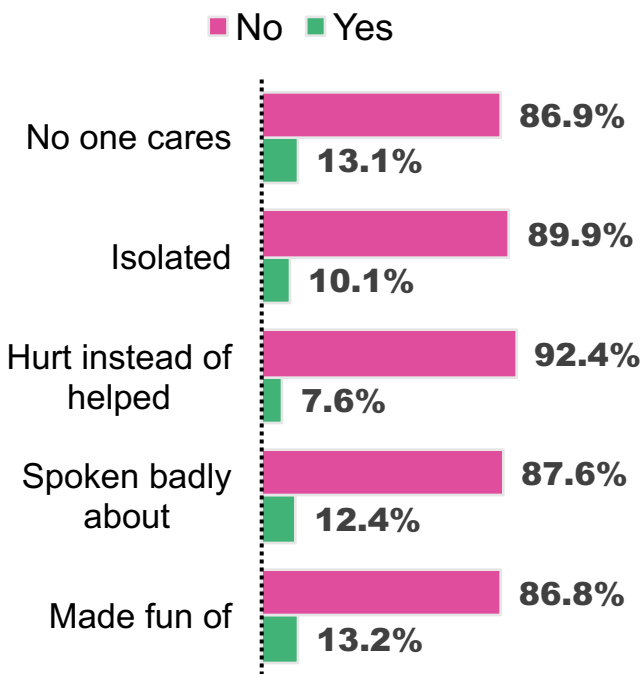
COMMUNITY CONNECTEDNESS

Do children feel like they are being supported by their community?

YES

Communities are central to supporting children affected by HIV and AIDS. However, research that works with this group has a tendency to focus on negative outcomes and associated measures; where it often neglects to report any positive findings outside an outcome of an intervention. However, within the Child Community Care study, children reported that they generally feel supported by their community.

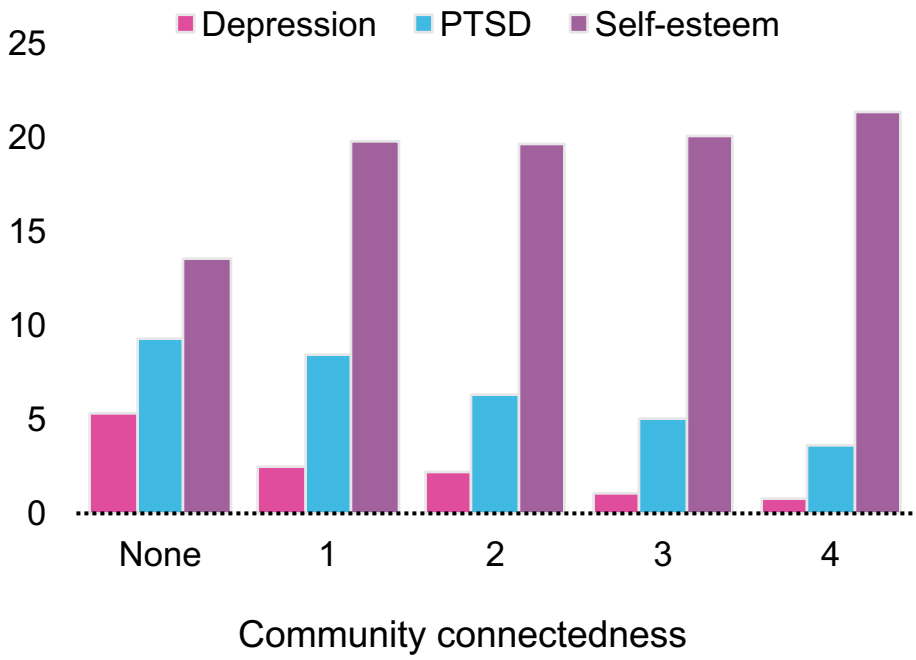




Children were examined across a range of questions about how accepted and supported they felt by their peers and community. Children mostly felt proud and that they fitted in with their communities, where they had lots of help and friends. Only a few felt that no one cared about them or felt isolated, hurt, made fun of and that someone spoke badly about them or their family.

Does feeling connected to the community have an impact of mental health?

YES



Engagement and support from the community is a core part of community-based interventions. As previously highlighted, children within the Child Community Care study feel as though they are supported and connected with their local community. This alone has been found to have positive implications for the mental health of children. Ranging from feeling disconnected and unsupported from the community (none) up to very connected with the community (4), the level connectedness with the community was examined alongside depression levels, trauma symptoms and self-esteem. Children's depression levels and trauma symptoms appeared lower with the strength of support and connectedness they felt with their community. Whereas, it appeared as though self-esteem increased greatly with support from the community, regardless of how connected the child felt they were.

THE HIDDEN NEEDS OF **MENTAL HEALTH**

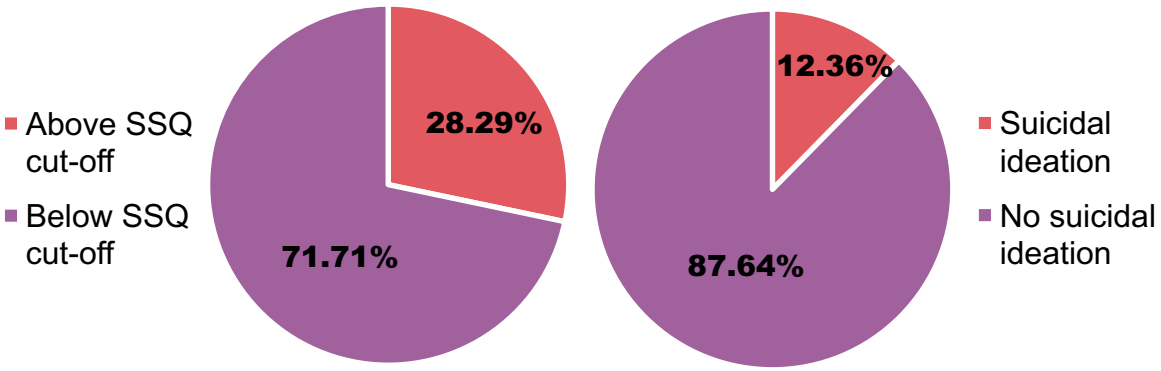
NO HEALTH WITHOUT MENTAL HEALTH

- PRINCE ET AL. (2007)

Mental illness presents a global burden and the number of individuals impacted by mental illness increases yearly. However, public health policy has a tendency to consider mental and physical health as separate in how they contribute to disability and mortality. This may result in an improvement of mental health being alienated from mainstream efforts to improve mental health. Inadequate attention is paid to the connectedness between mental illness and other health conditions and problems, therefore we need to begin integrating mental health with all aspects of health and social care.

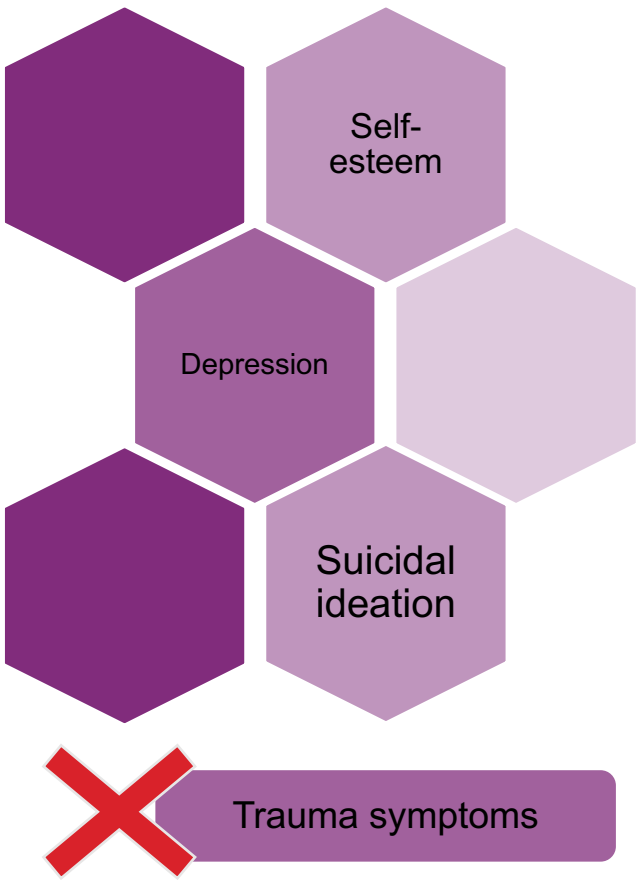
Carer mental health

The mental health of the carers was found to be associated with a number of factors such as unemployment, access to food and HIV status. The SSQ was a measure of mild affective disorders such as anxiety and depression and it was found that the majority of carers were below the cut-off for mild affective disorders. They were also mostly not reporting thoughts of suicidality.



Child mental health

Within the Child Community Care study, the self-esteem, depression levels, number of trauma symptoms and suicidal ideation was measured in children. Across the study, from baseline through to 12-15 months later, attending a CBO was found to improve self-esteem, and decrease the rates of depression and suicidal ideation. However, it did not impact upon trauma symptoms. By not improving more severe mental health issues, other types of care and support is needed.



DOES THE TYPE OF **WORKFORCE** INFLUENCE THE IMPACT OF A CBO?

YES

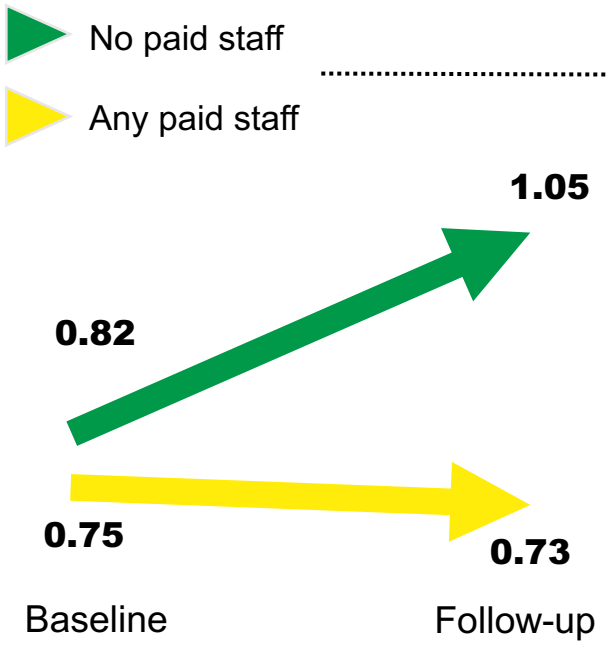
Any paid staff vs. team of volunteers

722 children with any paid staff

267 children with no paid staff

The Child Community Care study has brought to light the importance of paid staff and quality workforce factors within CBOs. Children who were provided support solely by volunteers were compared against those who had access to CBOs with paid members of staff. CBOs with paid members of staff still had the presence of volunteers, however this was alongside members of staff who were paid a wage. The psychosocial wellbeing of children within these two groups were compared at baseline and 12-15 months later.

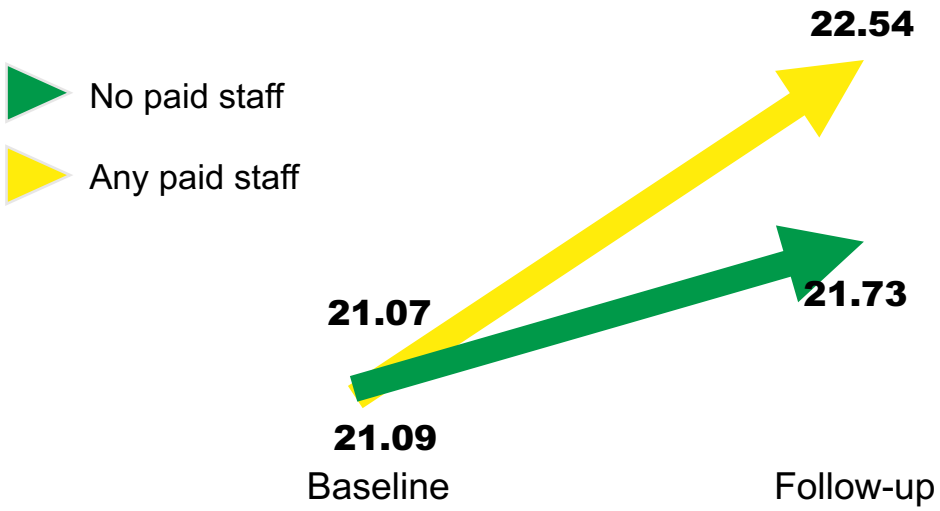
Educational risk



At baseline, the role of paid staff did not affect children's level of educational risk. However, at the 12-15 month follow-up children who only had access to support from volunteering staff were at significantly higher risk of being not being enrolled at school or in the correct class for their age. Children who were supported by any paid member of staff had a stable level of risk.

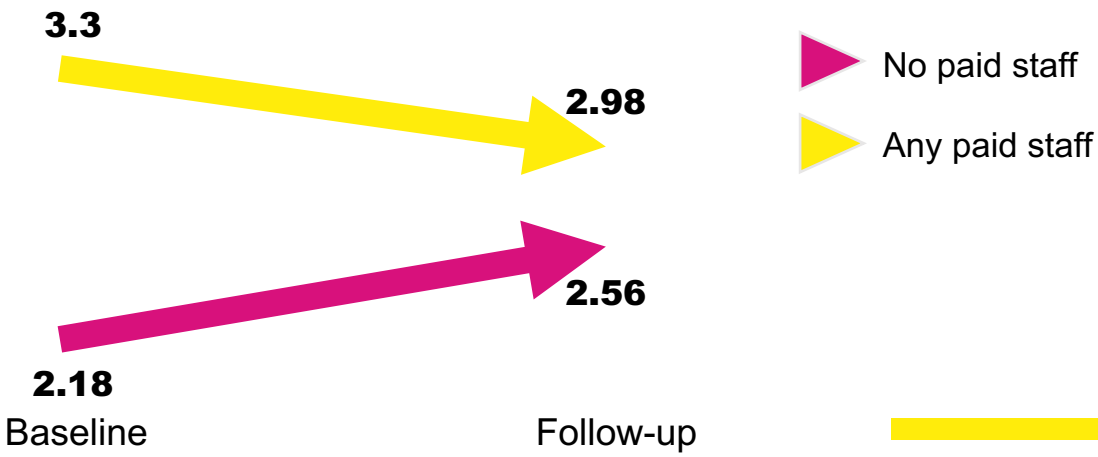
Self-esteem

Children's levels of self-esteem were also found to be influenced by whether staff were paid or volunteers. At baseline, both groups of children had almost identical levels of self-esteem. Although both groups had increases in levels of self-reported self-esteem at follow-up, those children who had access to any paid staff saw significantly greater increases in self-esteem than those who were supported only by volunteers.



Behavioural & emotional difficulties

Differences could additionally be found in behavioural and emotional difficulties children reported to have. At baseline, children who were supported by only volunteers had much fewer difficulties than children who had access to paid staff. However, children who were supported by paid staff showed a decrease in behavioural and emotional difficulties over time, whereas they increased in those supported by non-paid staff.

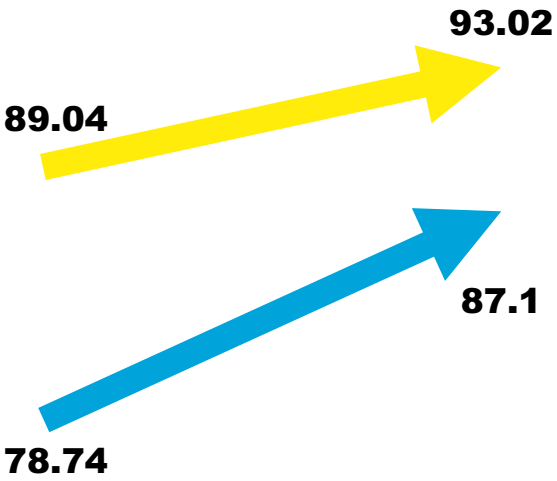


Stigma

Children who were supported by paid staff also showed significant improvement in levels of stigma they felt from their community. At baseline, both groups of children experienced similar level of stigma. However, 12-15 months later, children who attended CBOs with paid staff showed declined in feelings of being stigmatised, whereas they increased in individuals with access to only volunteers.

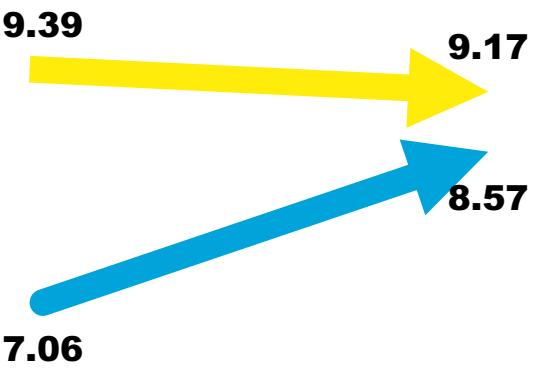
Child cognition

Draw-A-Person



Depending on whether children had access to paid or unpaid staff also had an impact on children's cognitive development. On the Draw-A-Person test children were asked to draw a set of people. Children who had access to any paid staff were better both at baseline and follow-up. However, both groups improved at follow-up.

Digit span



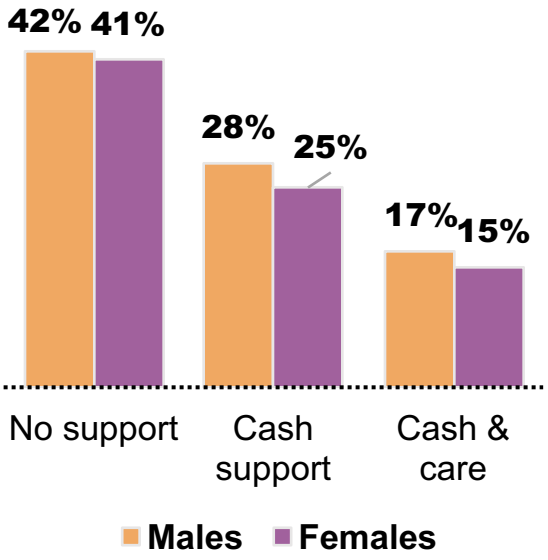
On the digit span test, which measures a child's ability to retain information by asking children to recall sets of digits highlighted no changes in ability at follow-up for children who had access to any paid staff. However, children who were supported by volunteers showed great improvement at follow-up, performing almost as well as the other group of children.

Mental Health

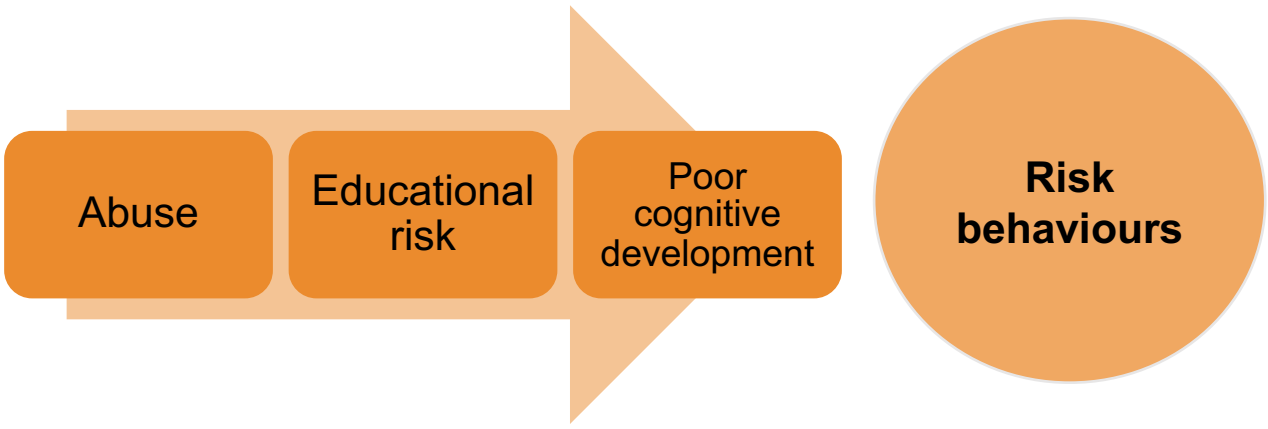
Whether or not staff were paid at the CBOs had no impact on more severe mental health problems. For instance, there were no differences between the two groups in ratings of depression levels and trauma symptoms. At follow-up, both groups saw a decline in levels of depression and an increase in levels of trauma symptoms.

CAN WE INTERRUPT
THE DOWNWARDS
SPIRAL?
YES

Cash, care & risk behaviours



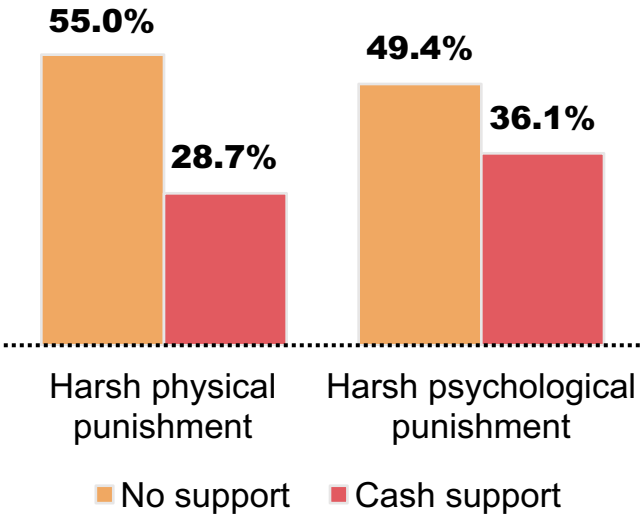
Many adolescents have been found to be involved in sexually risky behaviour, which can lead to a greater spread and transmission of HIV. These behaviours can be reduced with access to monetary support and the combined support of money and care (Cluver et al., 2014). Younger children are less likely to be involved in sexually risky behaviours. The Community Care Study can examine the effects of cash and care on the early pathways to such later risks. Key predictors explored were abuse, educational risk and cognitive development.

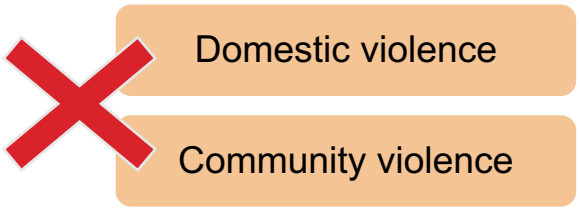


Abuse, educational risk and poor cognitive development have all been found to be pathways into sexually risky behaviour. Can providing monetary support or combined cash and care support to younger children reduce levels of abuse and violence, educational risk and improve cognitive development, and subsequently interrupt the pathways into risk behaviours? The Child Community Care study explored these three factors in younger children and how cash and care influenced these.

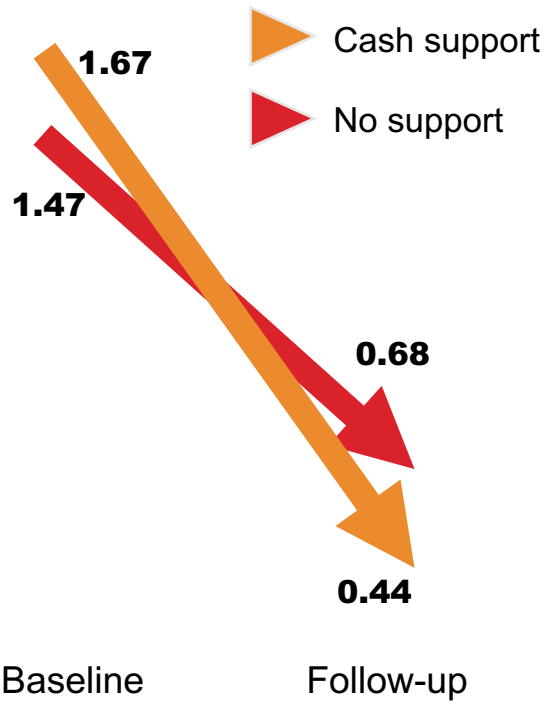
Violence

When examining abuse and violence that the children experienced, it was found that children who received cash transfers were exposed to significantly lower levels of harsh physical and psychological violence within their home. However, there was no reduction in domestic violence between adults in the home, or community violence.





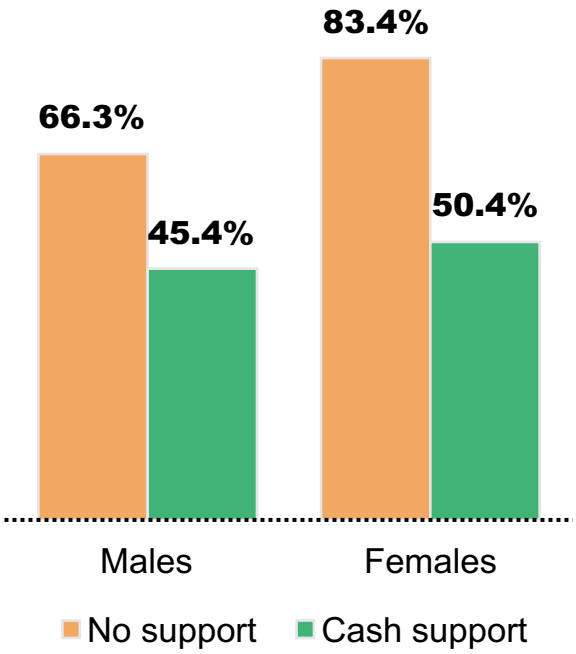
Harsh psychological punishment



The impact of cash support was examined at a 12-15 month follow-up. An effect was found in the levels of harsh psychological punishment experienced. Although both groups saw a decline in levels of violence, those who received cash transfers saw a greater decline over time than those with no cash grants.

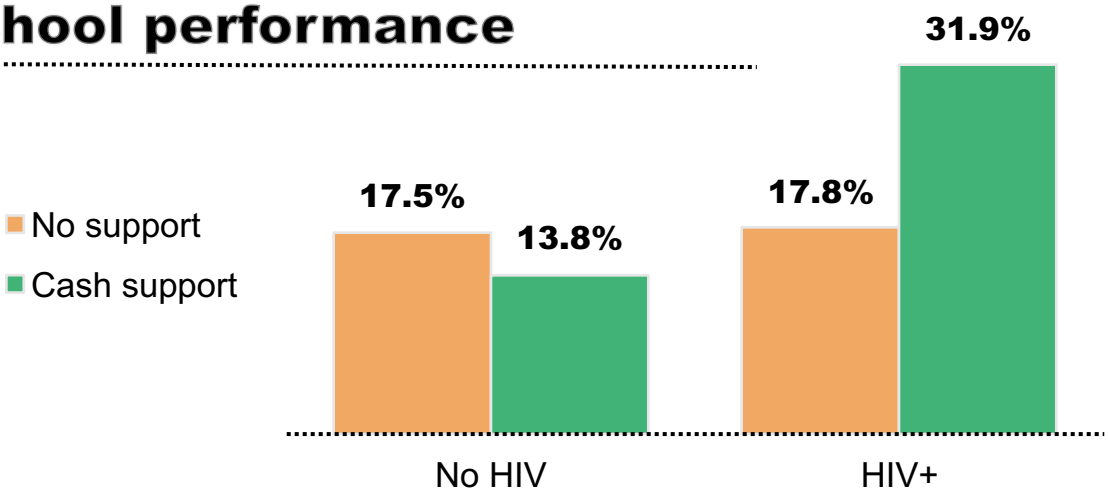
Education & cash

Correct class



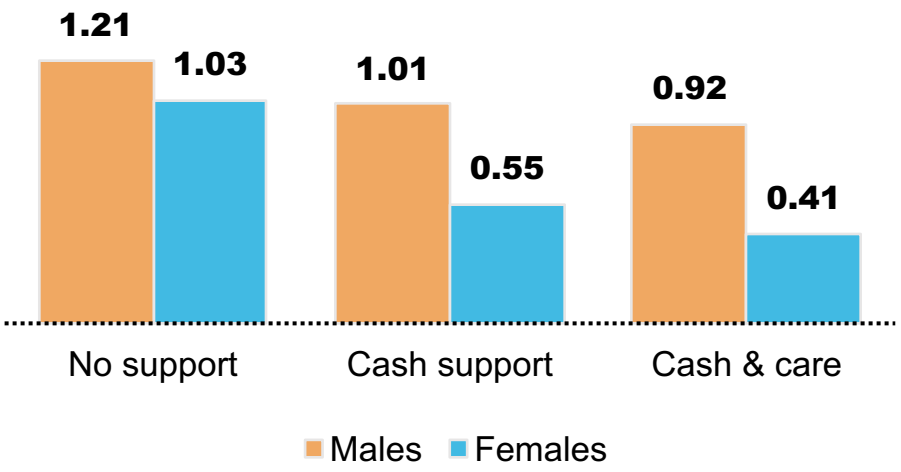
Risk to education and development can appear in a number of ways. One of these is whether the child is in the correct class for their age group. Boys and girls within the Child Community Care study differed in how cash grant support impacted their education. Although both groups saw a decrease in the number of children in the incorrect class with cash transfer support, girls showed the greatest decrease.

School performance



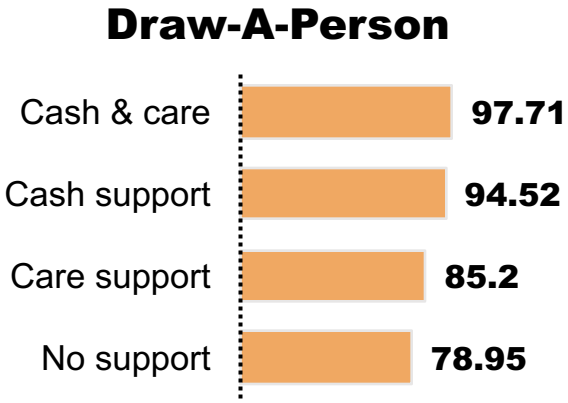
Another way in which educational risk is measured is through how a child is performing at school. Interestingly, children who were HIV-positive differed from those who did not have HIV. When provided with cash grants, children with HIV had a much greater increase in school performance, whereas children with no HIV remained at relatively the same level of performance, with or without a cash transfer.

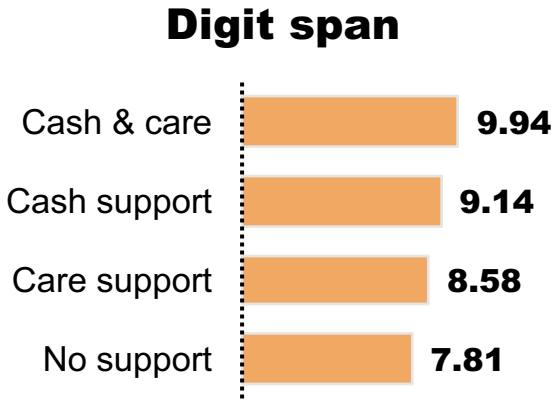
EDUCATION, CASH & CARE

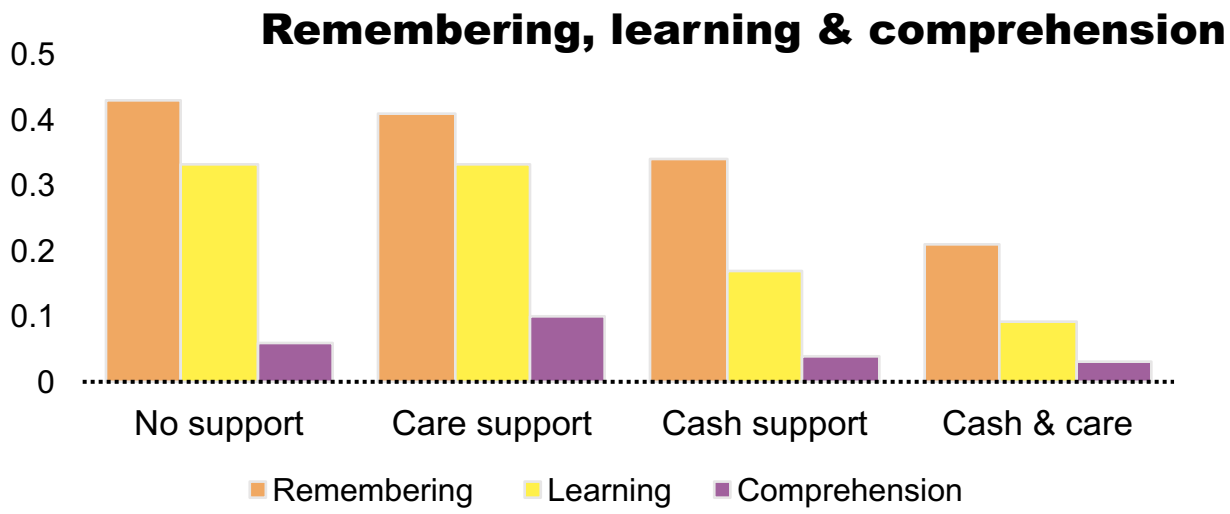


When all educational risks are combined for each child, boys and girls differed greatly in how they responded receiving only a cash transfer or combined cash + care. Boys presented no significant changes in educational risk with the support of cash transfers or cash plus care. However, girls had a significant reduction in educational risks upon receiving cash transfers or cash plus care in comparison to receiving no support. However, the addition of care support to receiving a cash transfer did not further reduce educational risk.

Cognitive ability







Children completed a number of cognitive tests including the Draw-A-Person test, a digit span test and further evaluation of remembering, learning and comprehension. Within the standardised digit span and Draw-A-Person tests, children who received both cash plus care support tended to perform the best. However, these scores remained similar to those children who just received cash transfers. In terms of the remembering, learning and comprehensive scores, difficulties with remembering was reduced most significantly with the combined cash plus care support, whereas difficulties with learning and comprehension was reduced most within both cash transfer support and cash plus care in comparison to receiving just care or no support.

CONCLUSIONS

Summary of the Child Community Care study

Implications for policy and programming

CBOs provide an important service for children living in high HIV affected environments who are exposed to a number of risks and who are highly vulnerable to risks to their psychosocial development. Ongoing funding for such organisations is an important provision to ensure the holistic provision of direct services to young children and the families. Overall, the Child Community Care study has provided sound evidence of the efficacy of community based provision and costing plans should integrate them into provision. CBOs should be targeted in efforts to improve capacity to mental health care provision at community level including can grow and adapt by incorporating specialised training, and more effective referral networks within existing health and social services to respond to these.

Service Structure

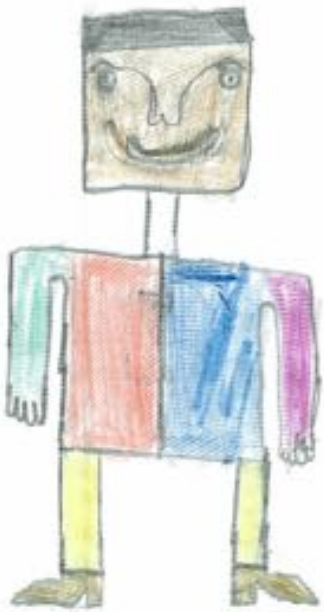
- Infrastructure considerations are important and the use of volunteers needs to be examined. Professional skill and development should be a key consideration in the provision of the psychosocial workforce.
- CBOs have the ability to reach the most vulnerable and their provision should be maintained to ensure that those at multiple risk are not missed.
- Cash transfers show promise for enhancing child wellbeing. When cash is combined with good care, the effects are enhanced. CBOs have multiple possibilities for contributing to the care elements and these should be included in cash transfer programmes to maximize their impact.

HIV

- Cognitive and developmental challenge for children infected, affected and living in high HIV environments is a challenge. CBOs are well placed to provide support and this should be a priority.
- In the HIV response, children infected with HIV, exposed to HIV in utero and those living in a household with any member who is HIV positive should be prioritized for care.

Caregivers

- Mental health of caregivers is an important factor in child development. CBOs are well placed to provide support for caregivers and a family approach which is inclusive and extends to wider family members should be routine
- Older caregivers do well – they should be encouraged and supported.



External factors

- Gender considerations remains a factor. Although girls may face disadvantage, our study shows that we need to provide for boys as well. In an attempt to close the gap for girl programmes need to avoid jeopardizing provision for boys.
- Country differences are present and programmes should be tailored to local circumstance, services, background health provision and cultural need.

Home & community

- Many children live in violent environments. Breaking the cycle of violence may be a very important element of ensuring that children reach their potential and thrive.
- Community connectedness is an important factor for young children and CBOs provide an opportunity for this.

What is the impact?

A publication within the Child Community Care study won a prize at the Cape Town ICASA conference for the best abstract. The study has been cited as one of the choice items for UNAIDS Science now. The email reports as follows:

The abstract of the article "How effective is help on the doorstep? A longitudinal evaluation of community-based organisation support" in PLoS One. 2016 Mar 11;11(3): e0151305. eCollection 2016 was chosen to be part of the 4th issue of HIV this month (2016), made available today at http://sciencenow.unaids.org. HIV this month contains abstracts or summaries of articles and reviews from scientific journals that are carefully filtered from a selection of close to a thousand articles and reviews over a period of one month. As author, you are invited to visit http://sciencenow.unaids.org/posts and provide comments, if necessary. UNAIDS Science now, is an interactive site that not only includes access to what's new in scientific journals, but also space for discussions and debates around HIV science. There is a more focused editorial section per HTM issue, and its clients/readership will be given the opportunity to articulate their opinions on specific issues. It aims to become the "go to" place for all of UNAIDS Geneva and field staff, co-sponsor organization staff, national AIDS offices, research institutions, university students and everyone with an interest in HIV.

The editors provided comments about the Child Community Care study:

This study is novel in both its research question and its methodology. The study aims to assess whether receipt of support from community-based organisations (CBOs) impacts the mental and social well-being of children in high HIV prevalence areas. The CBOs studied include many different organisations with diverse services, giving the study the benefit of assessing the overall impact of a combination of small, motivated groups. This helps lend credibility to CBOs and to convince policymakers and funders to support small-scale CBOs.

In terms of methodology, the study utilises two longitudinal datasets from southern Africa to explore the study aims. One survey is from a study of children affected by HIV served by CBOs, while the other is from a study of children affect by HIV without CBO support. There are some limitations to using two different studies, most especially unclear comparability and, in this case, lack of control data to adjust for possible differences, for example on socio-economic status or how HIV specifically affected the child. Despite these, this paper has striking results, and is an innovative effort to improve our understanding of the impact of CBOs on children's well-being and should spur further creativity in impact evaluation methods.

Published Papers

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3. Sherr L, Croome N, Bradshaw K, Parra Castaneda K. A systematic review examining whether interventions are effective in reducing cognitive delay in children infected and affected with HIV. AIDS Care. 2014;26 Suppl 1:S70-7. doi: 10.1080/09540121.2014.906560. PubMed PMID: 24720704.
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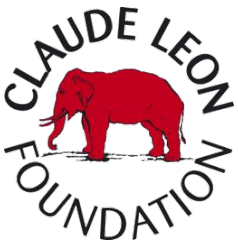
Contributors

Data collection for the Child Community Care study was funded by a number of organisations. Studies based in South Africa and Malawi were funded by Sweden Norad through a nesting agreement with HelpAge. Data collection in Zambia was funded by Unicef.

A number of partner organisations supported the development of a database of Community-Based Organisations that they were managing.

Young Carers Contributors

Our comparison group collected within the Young Carers study worked and were funded by a number of partner organisations.



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