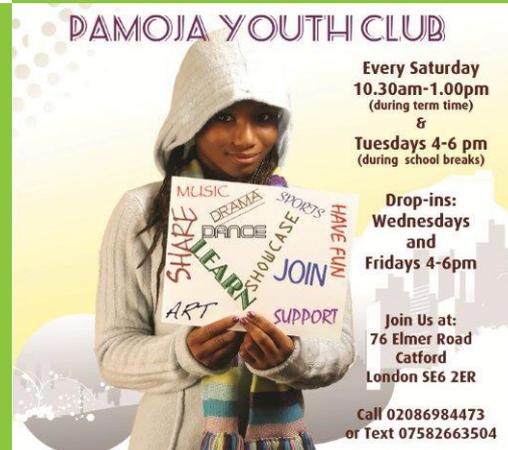


## Supporting young carers from families affected by HIV



### What is the initiative?

Pamoja Young Carers (Pamoja meaning 'Togetherness' in Swahili)

### Who runs it?

Africa Advocacy Foundation

### Who does it benefit?

Pamoja Young Carers supports primarily young African people aged 8–24 who are caring for their HIV positive parents or immediate family members in South London. Other beneficiaries include parents and siblings living with HIV.

### What does it do?

The umbrella organisation African Advocacy Foundation (AAF) delivers a range of community-based initiatives in Lambeth, Southwark and Lewisham to empower marginalized and disadvantaged communities to overcome poverty, ill health and social injustice.

Pamoja Young Carers Project, one initiative of AAF, works closely with families affected by HIV, faith and community leaders, schools, local social services and GPs to provide all round support for young carers. It raises awareness with professionals about how to positively engage with families. It also raises awareness with families about young carers' issues and the impact of caring on them, where culturally the concept of a young carer may be unfamiliar and where caring for a family member is often simply seen as part of normal life. The project also offers a range of targeted support for young carers such as respite activities, counselling, peer support and information and advice.

### When did it start?

2010.

## Why was it started?

AAF has been providing services to HIV positive African people, families and community partnerships over the past 16 years and has a strong grassroots network. There had also been a previous generic young carers service. From this work AAF became aware that there were a high number of young carers from families affected by HIV whose needs were seemingly not being recognised by social services, schools or other agencies.

The service was aware of incidences where young people's mental and physical health were being negatively impacted upon due to their inappropriate and substantial caring roles. In particular there was a lack of recognition of the role of young carers within the African communities. Coupled with the stigma related to HIV and the lack of faith and culturally appropriate services, young carers were being isolated and were not accessing services available to other young people such as school support, training, youth services, career advice and social activities. Pamoja Young Carers was therefore set up.

## What are the aims and objectives?

### Aims:

- To reduce the physical and emotional extent and impact associated with inappropriate caring responsibilities.
- To support, give advice to and empower (primarily) African young carers aged under 24 caring for a family member affected by HIV in South London.
- To enhance a collaborative approach to supporting vulnerable and isolated young carers by working closely with families, faith and community leaders, schools, local social services, GPs and other agencies and professionals.

### Objectives:

- To raise the awareness of young carers' needs in the community and among professionals and the effects of stigma, isolation and deprivation on young carers.
- To work with families to help reduce the extent of inappropriate caring roles.
- To provide respite and activities for young carers from their caring roles.
- To facilitate access to sensitive, confidential and culturally appropriate information and support based on assessed needs.
- To help facilitate the personal development of young carers, such as increased assertiveness, self-esteem and social skills and to enhance their career opportunities.
- To promote collaborative, inter-agency work and the sharing of learning and best practice.

## How is it funded?

The Young Carers Grant Programme 2010, managed by Carers Trust and funded by Comic Relief.

## What has it achieved?

“The outing sessions and trips are fun because we get together and enjoy lots of activities away from home.”

**Young carer**

“Dealing with HIV disclosure issues is not easy. Pamoja project made it easier for me to talk to my children about my HIV status.”

**Parent of a Pamoja young carer**

“I had little understanding of issues surrounding young carers whose parents live with HIV. My involvement with the Pamoja group has given me the confidence to address issues without fear of upsetting the family and young people involved.”

**Children and Families Worker**

The project has successfully engaged and worked with 112 young carers and their families, the majority of who are also supported through other AAF services such as those affected by HIV, female genital mutilation, mental health, and domestic violence. 76 of these young carers are formally registered with the Pamoja project with the remainder accessing the wider Youth4Life club.

So far, the project has successfully raised the awareness of young carers and the related issues with 158 African parents, 17 faith leaders, professionals and over 300 members of diverse communities in South London. Awareness raising takes place in a range of ways such as through family visits, events, workshops and peer support groups for parents. Young carers on the project are involved in this by attending and delivering presentations themselves.

Confidential discussions with young carers have helped highlight their fears, wishes, needs and feelings about caring and life in general. It has helped the majority of young carers to have a more positive outlook on caring, the important roles they play as carers and to feel better knowing that they can speak to someone if faced with a situation. Support and participation in group activities, outings and youth clubs has helped reduce feelings of sadness, isolation and the shame linked to the double stigma of HIV in the family and caring. For many it has led to increased social skills and increased their confidence and ability to openly share experiences and concerns as young carers.

Often families have not previously sought assessment of their needs from statutory services due to the fear of disclosing their HIV status with the community, schools or to other professionals. Engagement with families, therefore, has enabled better assessment of young carers and the needs of the family which has led to more, effective liaison with other professionals working with the family.

Families with whom the project has worked have an increased understanding of the dangers of inappropriate caring and a greater appreciation and recognition of the rights of the child. There is also reduced secrecy and denial of the caring roles undertaken by their children and increased willingness to engage with professionals without fear of family secrets being compromised or personal data mishandled.

Parents and children are better able to talk to each other about issues and 37 parents have been assisted to disclose and discuss their HIV status with their children. This has helped some of the young carers to look at caring in a different way.

As the Pamoja project is the only organisation in South London currently running formal and regular programmes for young carers from families affected by HIV, it has gained recognition among other carers services locally and beyond

## How have young carers and their families been involved in planning and delivering this work?

A project steering committee of young carers helped develop the Pamoja project proposal and the committee currently oversees planning and spearheads its delivery. This includes outreach and raising awareness in the community and with professionals as well as organising outings and trips, befriending sessions, workshops and club activities, and designing project resources such as leaflets and the website. Young carers also participate in the monitoring and evaluation of the project.

Respite for young carers comes through AAF volunteers who provide caring breaks each month. As a result of more parents being able to disclose their HIV status, the peer support groups for adults living with HIV run by AAF have seen an increased number of parents volunteering to provide caring breaks for other parents with HIV, whose children have caring roles, thus providing respite for these young carers. The AAF Peer Support Coordinator therefore links closely with the Pamoja project.

Feedback is also gathered from young carers and parents through surveys and anecdotal evidence and feeds into external evaluation reports, internal reviews and future plans.

## How is the initiative run?

The Pamoja project is for young carers aged 8–24, (with a current range of 11–21). It is managed by a Project Coordinator who is supported by four volunteers who themselves are young carers.

An additional team of ten trained young mentors (young carers themselves) are at hand to support the work.

There are two strands of the project; the first being around outreach, awareness and education.

Caring by children is a cultural norm in African communities and because of that, children's rights to education, for example can be overlooked. The Pamoja Project works, therefore, with the community and families – not to condemn but rather to raise understanding about the negative impacts of being a young carer and to offer solutions to support families.

Two community awareness workshops are run annually to raise the issues faced by young carers and particularly those related to HIV stigma and discrimination. Young carers, parents, community members and faith group leaders within the African community attend each event.

Pamoja also works closely with The Children's Society, Lewisham Carers, Lambeth Carers Hub, Southwark Carers, local childrens partnerships and other services to highlight the role of young carers from families affected by HIV and share learning and best practice. This has increased awareness among professionals and referrals to and from other services to the project.

One of the main ways that young carers begin receiving bespoke support is when they are accessing the Youth4Life activities programme – another AAF initiative. Through this generic youth programme young carers may be accessing activities such as homework support, arts sessions and outings. Because of the issues of stigma, offering specific young carer interventions privately to those young people once they have been identified as young carers is necessary. Specific young carer interventions may include caring assessments, breaks and family case conferences. Once the young carer has grown in confidence and is ready to be recognised as a young carer and to participate in support groups, they are often happy to openly share their caring experiences, mentor new young carers themselves and be an ambassador for the work of Pamoja at events.

Engagement depends on good relationships and trust built up with families. Working with families living with HIV through the wider work of AAF, has provided opportunities to discuss issues with parents such as who helps to care at home. Issues about school (such as children underperforming, being late or absent) are often a platform for discussion of the benefits of the Pamoja project which in turn brings young carers into the project.

Similarly, engaging families and young people attending AAF and partnership community health events such as HIV specific workshops, faith based health events and young peoples health workshops provide opportunities for bringing young carers onto the project.

The team of young mentors is also involved in awareness raising activities in the community and with professionals, talking to and recruiting other young carers.

The second strand to the project is the provision of targeted support for young carers. The Pamoja Young Carers Club provides homework support and a wide range of youth activities. Monthly weekend outings and a summer activities programme is run to a wide range of venues and activities such as to carnivals, galleries, theatres, bowling and youth events.

Individual support sessions are offered to young carers where they can be assessed and referred to other support. Information, advice and guidance is provided. A young carers information pack consisting of a pen, diary, caring information booklet, a feedback form and links to other services and resources is given to each young carer. Posters, and information leaflets are distributed to local schools, GPs, mosques and churches to promote the service.

The project also facilitates bi-monthly peer support and discussion groups for young carers to discuss their experiences and needs. These groups for eight to 12 young carers are organised and run by the team of 15 trained young carer mentors who also help in running club activities and befriending. Mentors will also support and advocate for peers on a one-to-one basis.

A combination of tools and methods are used to assess levels of need, resilience and wellbeing of the young carers including the Multidimensional Assessment of Caring Activities (MACA) and Positive and Negative Outcomes of Caring (PANOC) tools from the Manual of Measures of Caring Activities and Outcomes for Children and Young People.<sup>1</sup> Other data comes from focus groups, interviews and feedback

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1 Tools from Joseph S, Becker F, Becker S (2012), 'Manual for Measures of Caring Activities and Outcomes for Children and Young People'. Carers Trust.

sessions with young carers, parents and professionals and faith leaders. A range of methods are used including young carers' activity diaries, school liaison reports and questionnaires.

The project aims to continue empowering young carers with skills and opportunities to play leading roles in the delivery of interventions for young carers and to continue to learn from the young carers themselves, families and other young peoples services.

Additionally, each year, staff and volunteers deliver between 60–70 family outreach support sessions in families' homes and the project will often hold family case conferences and make referrals to other agencies for additional support.

## What methods have been particularly effective?

Over the life of the project, it has consistently observed that the majority of young carers are initially ashamed to admit their caring roles and do not want their families' HIV issues highlighted in the generic Youth4Life project. In order, therefore, to address the double stigma experienced by young carers as a result of HIV and the shame often associated with caring as a young person, the project has embarked on a strategy to normalise HIV among the peers of young carers, families and the community in general.

Key has been ensuring group sessions celebrate young carers' lives and reflect their valuable contribution to their families. It has also been important to ensure sessions are light hearted by using ice breakers, poems, art, rap and stand-up comedy on topics such as 'Why I am a busy person' (in a comical sense/with a humorous touch), 'Test of HIV knowledge', 'Family Love', 'Why you are my Friend'.

## Have there been any challenges along the way?

The majority of the families and young carers still do not recognise the active roles the young people play as carers and newly engaged young people themselves are usually hesitant to be referred to as young carers as they feel this unnecessarily labels them.

The project has not received any self-referrals from young carers despite the efforts spent publicising the project. This is mainly due to the existing levels of HIV stigma in the community and the fear of being labeled as carers. All new carers to the project have joined through referrals by parents, friends, church or family interactions with the charity or through project staff outreach and recruitment efforts.

## What hints and tips might help me get started?

- Young carers are unique people with a unique set of needs and require patience and understanding. Address sensitive issues privately but also engage them in group tasks and activities.
- Young carers are enthusiastic and very energetic. Involve them in all that you plan to do and give them the freedom to lead activities.

## Are there any useful documents or resources that could assist me?

Further information about the Pamoja project and the Youth4life activities can be accessed from the main Africa Advocacy Foundation website [www.a-af.org](http://www.a-af.org).

Carers Trust has commissioned an external independent evaluation of this project which will be available in 2014.

### Where can I get further information?

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