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TASO UGANDA

THE INSIDE STORY

Participatory evaluation of HIV/AIDS counselling, medical and social services 1993 - 1994

The AIDS Support Organization (TASO)

World Health Organization (WHO)

TASO MULAGO MUSIC, DANCE AND DRAMA GROUP SONGS

1. UNITED AGAINST AIDS

Chorus: United against AIDs
Unite and be safe
Get the facts and get to know
What AIDS is all about.

1. We want to thankall those, that gave in their lives.
They stood firm to fight AIDS, NOT people with AIDS.
Chrs.

2. So many brothers, sisters, relative and friends
Have left us and may are to go,
There is nothing we can do.
Chrs.

3. So many friend reject me,. But why neglect me
Why do you leave me, why do you go away
When we were so close.
Chrs.

4. So many time I'm worried, and other times I'm crying
So lets get together and fight
Until we reach the end.
Chrs.

5. So lets all get together, and encourage ourselves
Together we stand and fight
Until we reach the end.
Chrs.

Composed by Tonny Kasule

The song is sang by TASO Music Dance and Drama Group
The AIDS Support Organisation.

2. WHEN WE COME TOGETHER

Chorus When we come together, we feel at home
When we sing together, we enjoy and dance
But when we loose one member we feel lonely
Why don't you come together and sing a song.

1. However much we cry, it doesn't help
And if you sit at home we lose our weight
Because we think of death, I tell you day and night
Why don't we come together and sing a song.
Chrs.

2. When we look around, so many people are sick
Because they have the fear about the disease
We also have the same, we're fearing death
Why don't we come together , and compose we a song.
Chrs.

3. We thank our counsellors and doctors
For what ever they do
Because we fight together against the disease
So when we fight together, we forget the disease,
Why don't we come together and we feel at home.
Chrs.

4. When we go back home, we feel lonely
But when we come together, we feel at home
Because we dance, discuss and enjoy ourselves
But why don't we come together, and sing our songs.
Chrs.

5. So when we come together, together we fight
And when we sing together, we feel at home
So when we talk together, we forget the disease
Why don't we come together, and enjoy ourselves.
Chrs.

Composed by Fred Kanakulya

3. WHY, WHY ME ?

Chorus: Why, why me, why you, why she, why him, why we?
We're wondering why this came to us, but Lord why me?
But Lord why me?

1. We're wondering whether this pain will be overcome,
For us to be free from AIDS and enjoy as we used to do,
We've been rejected by the members of our families
We are appealing to you with us now with support
We can survive.
Chrs.

2 We've a lot to say despite of being rejected
Fellow youth you have failed to understand
And believe in what we say
Youth we're warning you the disease is very rampant
A friend in need is a fiend indeed
Fellow youth we're warning you.
Chrs.

3 AIDS has no Marcy for those who think they know better,
This message is good for all those who think we're useful
Because this may be the only chance to share with you new ideas
Tomorrow it may be very late for you to see me again.
Chrs.

.4. We wish TASO was there earlier on, we would be free from AIDS,
And none of us would be infront exposing this to you,
BUT because we didn't get the chance of knowing what AIDS was all about.
We've got to fight together with you and live alone the past.
Chrs.

Composed by Fred Kanakulya

HIGH LIGHTS OF 1998

- To-date TASO has a cumulative client registration of 50,911; 34% male and 66% female.
- TASO registered 7445 new clients in 1998 as opposed to 4787 in 1997.
- There was a percentage increase of 56% in client registration in 1998 compared to 1997.
- 15,778 clients were served in 1998 as compared to 11,033 clients served in 1997. Thus suggesting a percentege increase of 43% in 1998.
- The percentage increase could be attributed to increased awareness, more HIV testing facilities, community activities and improvement in record keeping.
- In 1997, more clients recieved medical services (9984) as compared to counselling (9799)
- In 1998, more clients recieved counselling services (13,953) as compared to medical services (13,860)
- A total of 50,323 counselling sessions were conducted (43,200 for registered clients & 7123 for non-registered clients)
- A total of 54,482 medical visits were conducted (51,824 for registered clients & 2658 for non-registered clients)

- **In 1997, more clients recieved medical services (9,984) as compared to counselling (9,799)**

- **In 1998, more clients recieved counselling services (13,953) as compared to medical services (13,860)**

- **A total of 50,323 counselling sessions were conducted in 1998 (43,200 for registered clients & 7123 for non-registered clients)**

- **A total of 54,482 medical visits were conducted in 1998 (51,824 for registered clients & 2658 for non-registered clients)**

- **831 (11%) of the clients registered in 1998 were children below the age of 15 years; with a minimum age of 1 year, maximum age of 14 and mean age of 3 years.**

- **Clients at registration reported having 19278 living children; indicating a potential heavy orphan burden. It should also be pointed out that over 45% of TASO clients are single parents.**
- **Respiratory tract infections were the commonest symptoms diagnosed in 1998; 21% .**

- **Percentage of adults (yrs >=15) who had an STD exam among those who recieved medical services was 3,117(25.3%)**

- **Among the individuals examined for STDs, 72.5% had an STD detected.**

- **The number of individual clients treated for STDs in 1998 was 3,724 . However the number treated for STDs exceeded the number examined for STDs.**

- **23% of the individual adult clients reported using various family planning methods**

- **Home visits accounted for 2.6% of the medical visits in 1998 and 11% of the counselling sessions.**

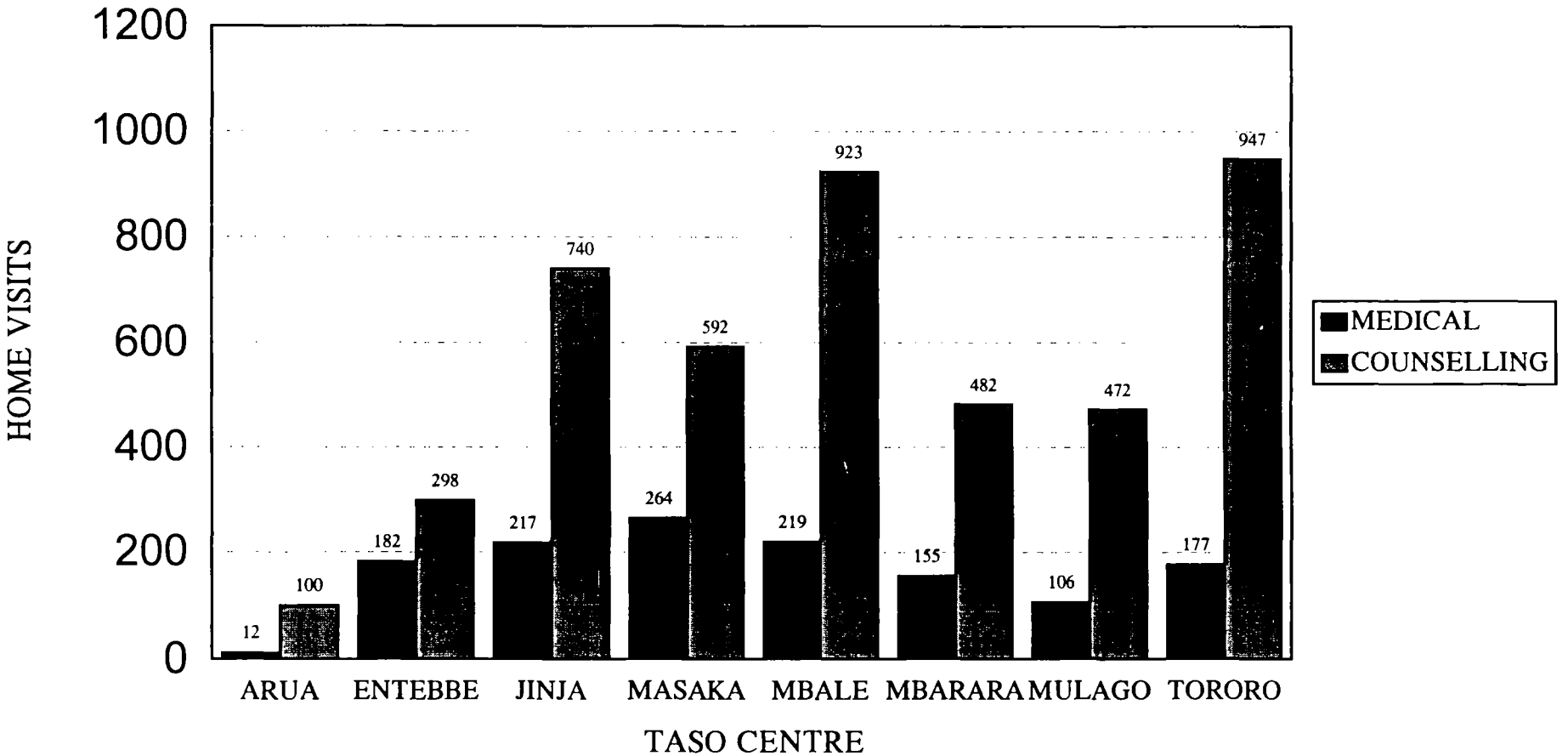
- **The average number of medical visits in 1998 was 4 per client, with a minimum of 1 medical visit and a maximum of 38 visits.**

- **Clients were referred to other specialised medical services outside TASO 126 /51824 (0.2%). This is extremely a small number. The major problem here is the poor completion of the instruments of data collection.**

- **However this is a measure of the level of TASO's collaboration with other organisations.**

- **3.2% of TASO clients were reported dead in 1998. This number could be an under estimation. At least 80% of these clients had TB /URTI diagonised by TASO medical staff.**

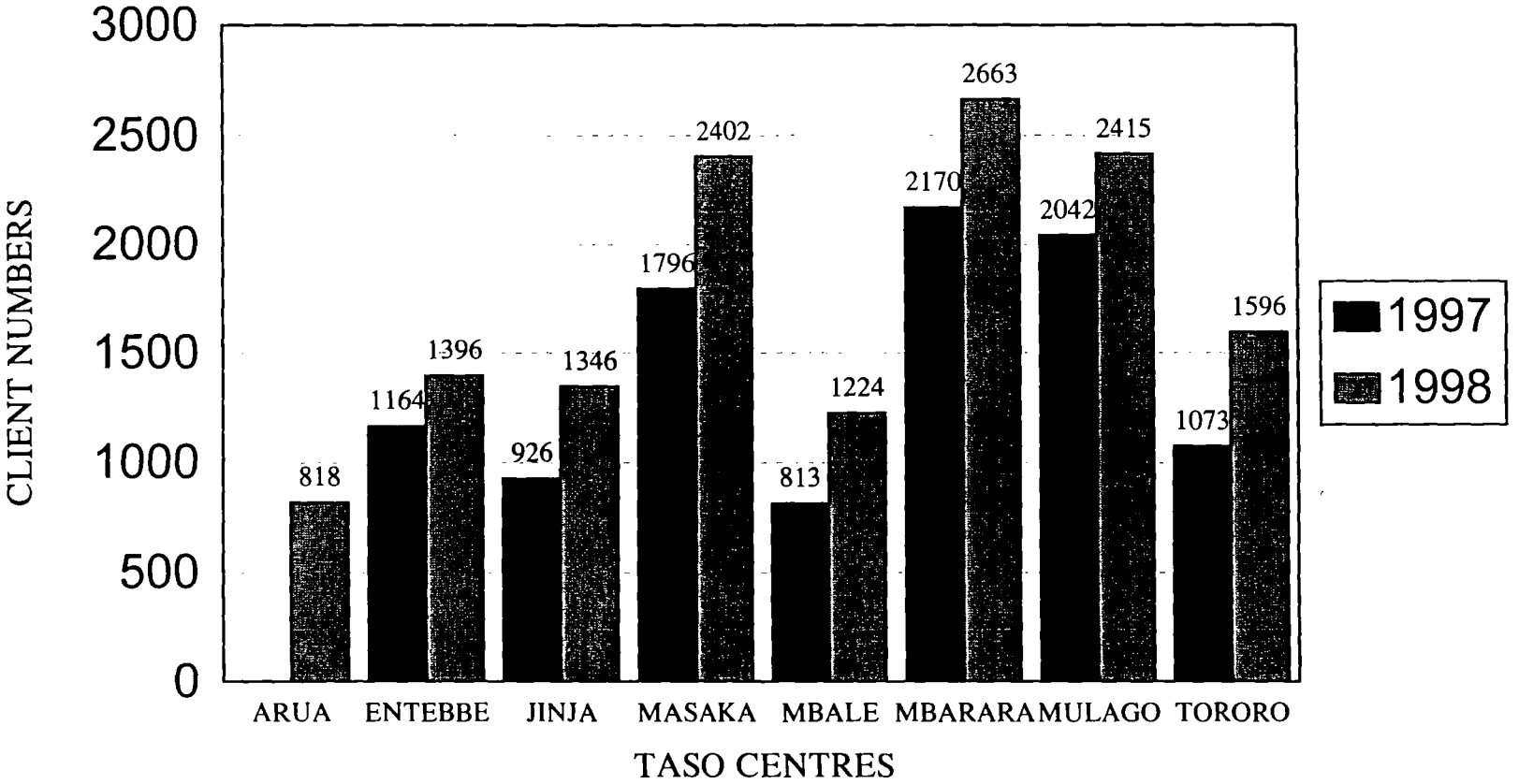
REPORTED HOME VISITS MADE BY MEDICAL AND COUNSELLING DEPARTMENTS IN 1998



Home visits by medical staff accounted for 2.6% of the total medical visits in 1998. Counsellor home visits accounting for 11% of the total counselling sessions. There is a need to strike a balance on who should be expected to carry out more home visits taking into account these are sick people being home visited.

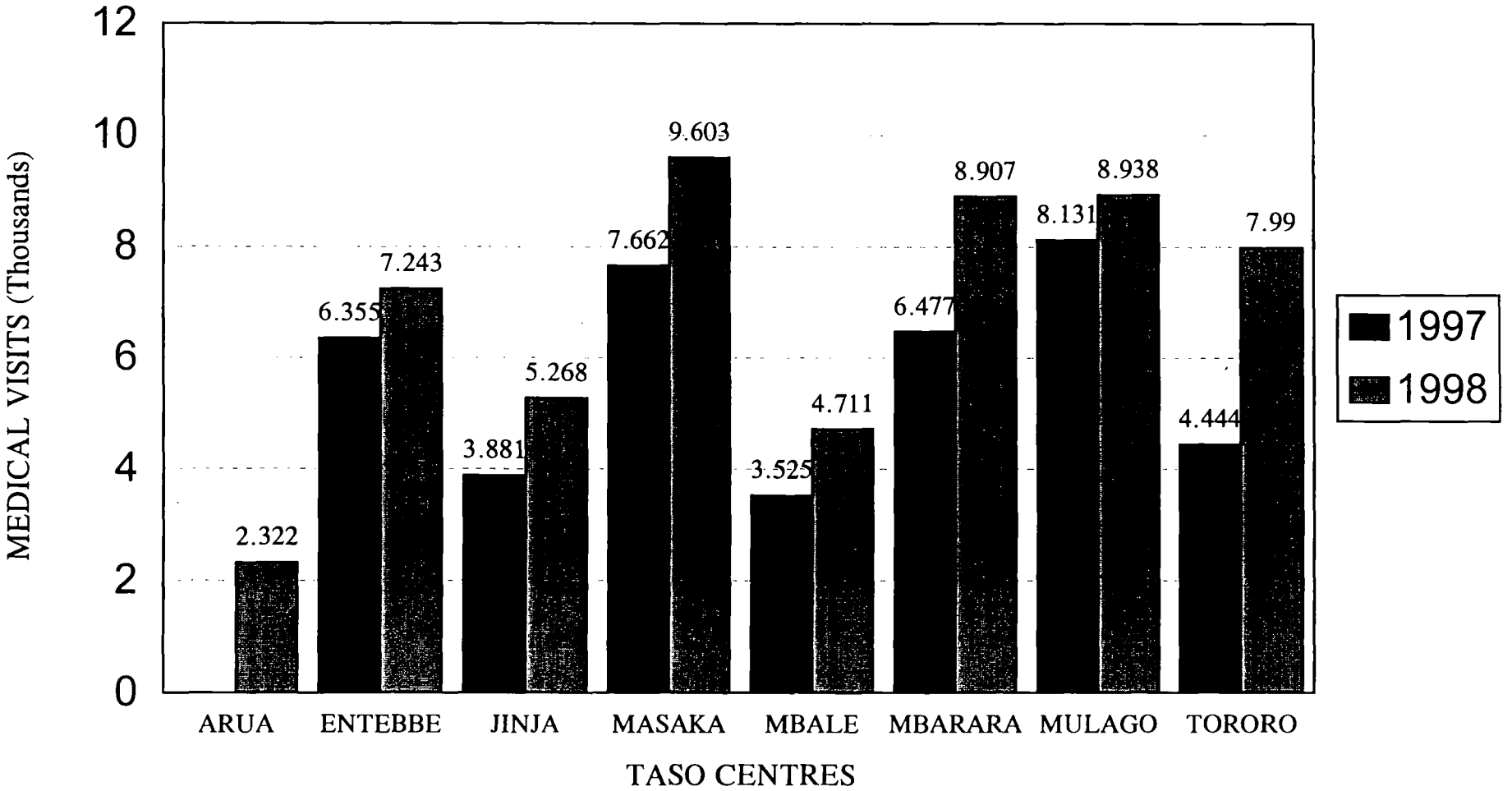
A COMPARISON OF INDIVIDUAL CLIENTS

RECIEVING MEDICAL SERVICES IN 1997 AND 1998 BY CENTRE

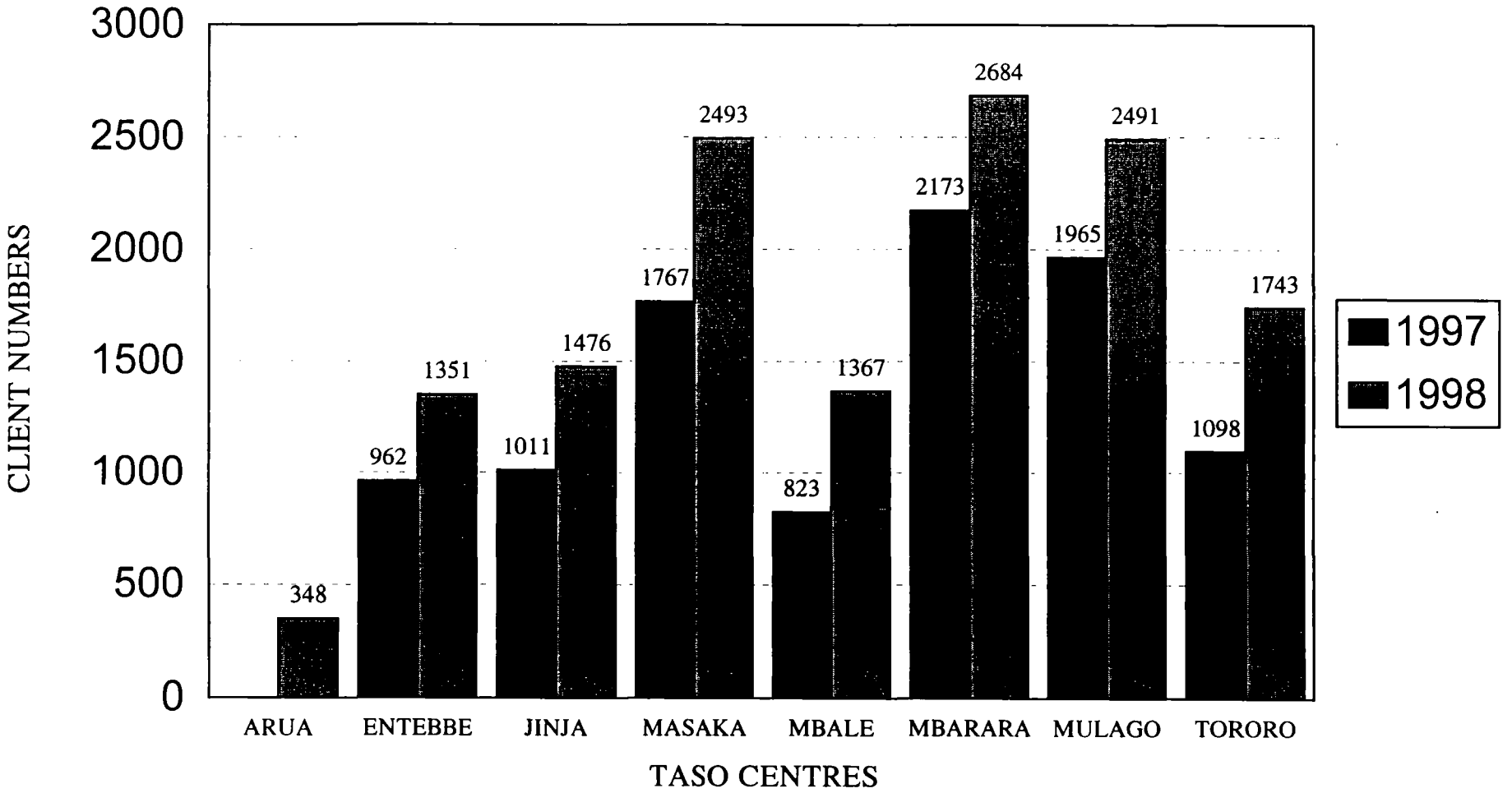


In 1997, 9984 clients recieved medical services as compared to 13860 in 1998; i.e there was a 39% increase in the number of clients medical services in 1998.

TOTAL MEDICAL VISITS FOR 1997 &1998 BY CENTRE

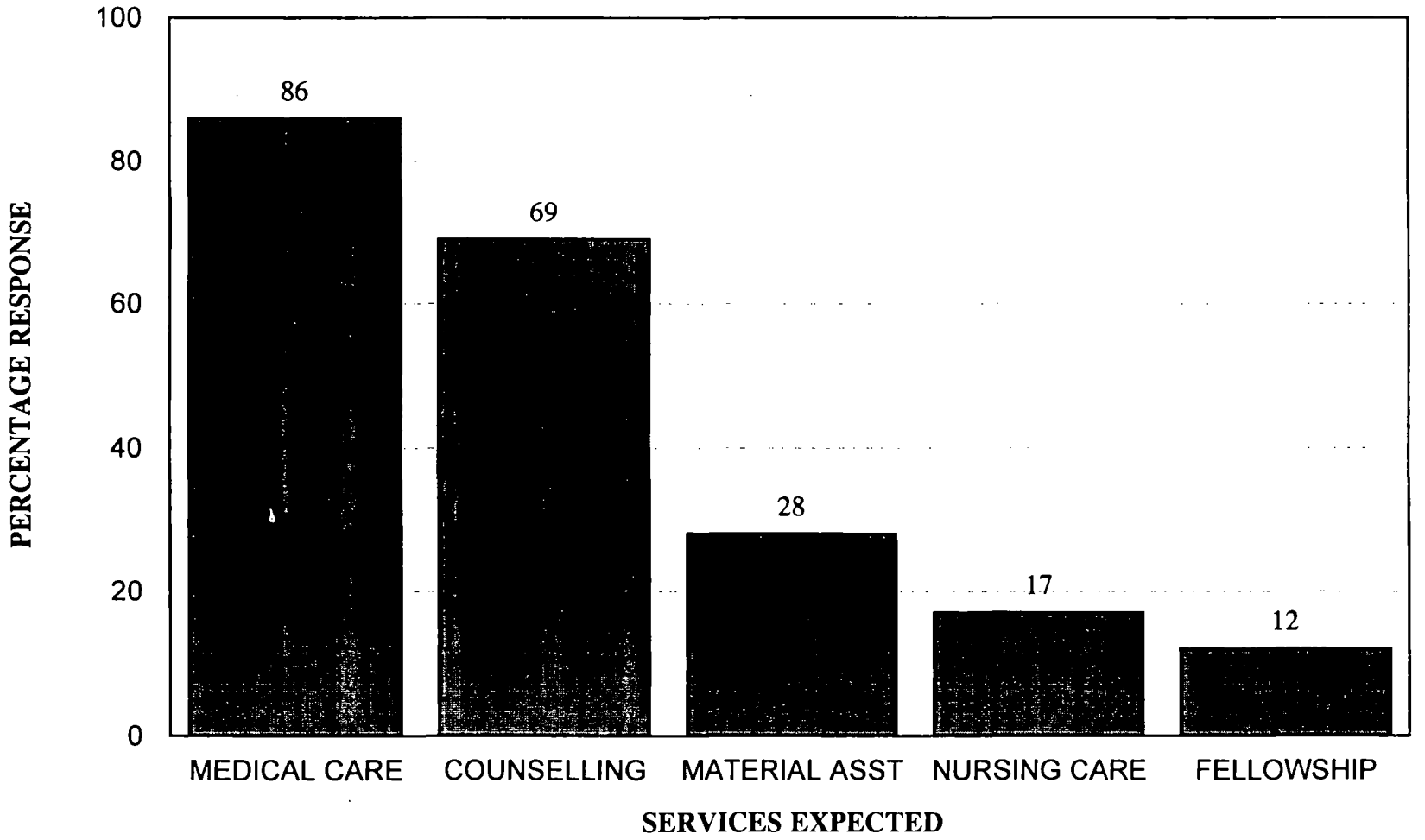


A COMPARISON OF INDIVIDUAL CLIENTS RECIEVING COUNSELLING SERVICES IN 1997 AND 1998 BY CENTRE



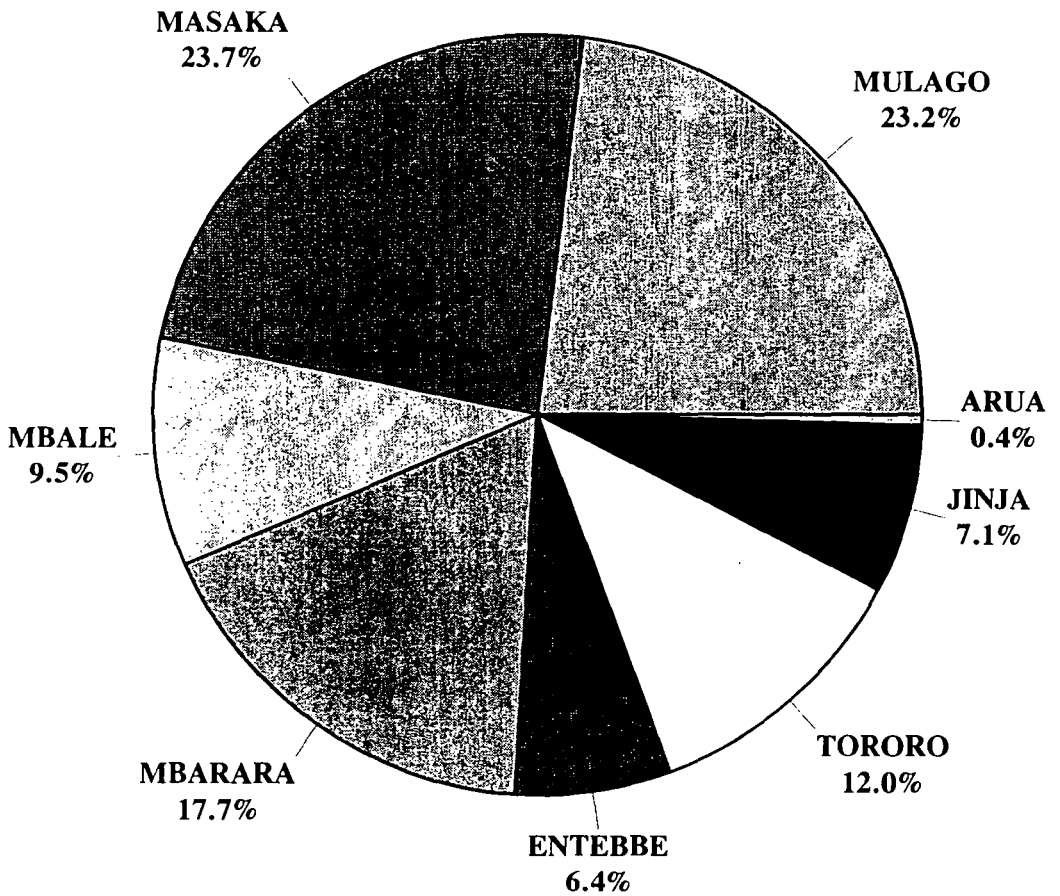
In 1997, 9799 clients were counselled as compared to 13953 in 1998; i.e there was a 42% increase in the number of clients counselled in 1998.

RESPONSES TO EXPECTED SERVICES BY NEW CLIENTS IN 1998

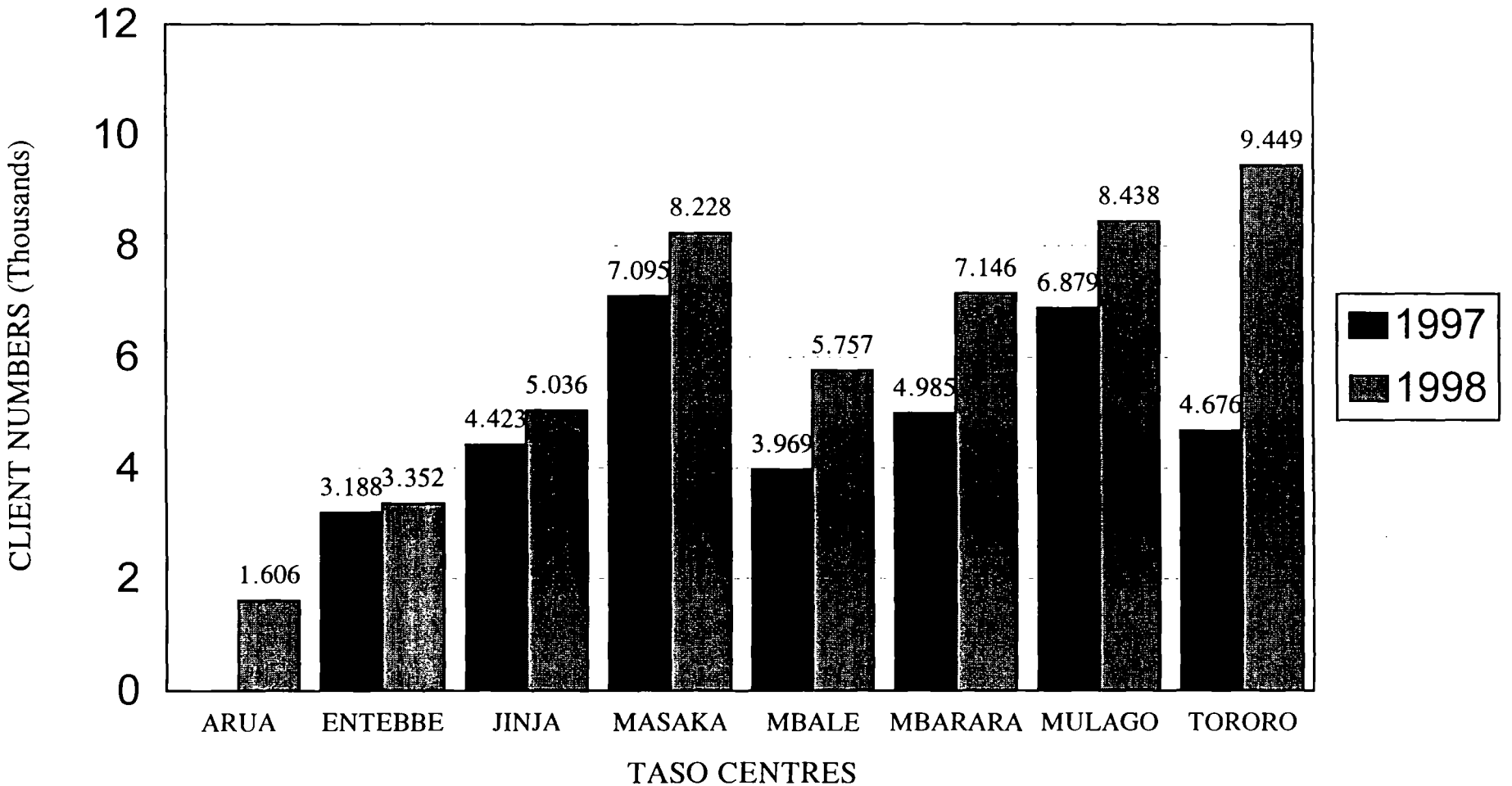


CUMULATIVE CASO CLIENT REGISTRATION BY CENTRE

AS OF 31/12/1998; (N = 50,911)



TOTAL COUNSELLING SESSIONS FOR 1997 & 1998 BY CENTRE



TASO REGISTERED CLIENTS AND THEIR REPORTED CHILDREN

Year	Registered clients	Children	Dependants
→ 1996**	40.000	105.000	?
1997*	**6.000**	**15.000**	**?**
1998*	**7.500**	**20.000**	**?**
1999**	7.500	20.000	?
2000**	7.500	20.000	?
2001**	7.500	20.000	?
		200.000	????????

* Data from TASO MIS 1997 and 1998

** Estimated from 1997 and 1998 data

- 160 children are currently supported by TASO
- CORE, the cost and revenue analysis, gave the following annual costs of the TASO support to one child:

⇒Jinja 110.000,- Ush

⇒Mulago 450.000,- Ush

⇒Masaka 370.000,- Ush

⇒Mbale 150.000,- Ush

⇒Mbarara 210.000,- Ush

⇒Average 250.000,- Ush

VISIT BY DELEGATES OF THE UNITED STATES TO TASO MULAGO

Arrival : 10.30am

Welcome remarks and overview of TASO : Head of Mobilization and Advocacy 10.30-10.40am

Brief on TASO Mulago services: Manager TASO Mulago: 10.40-10.45am

Moving around to have a look at some of the services: 10.45-10.50am

Interraction : visitors , TASO staff, children and body positive mothers : 10.50-10.55am

Song by TASO Mulago Drama group: (United against AIDS) 10.50-10.55am

Talk on Child support: Counsellor (Emilly) : 10.55am-11.10am

Personal experiences from Child support beneficiaries: Ivan,Olivia,etc

Remarks by Representative of the US delegation : 11.10am- 11.25am

Song from TASO Mulago Drama group : 11.25-11.30am
and closure

TASO

The AIDS Support Organization

Uganda

Ten Years: 1989-1998

History of TASO and Trends in Service Delivery & Utilization

The AIDS Epidemic in Uganda

- AIDS or "slim" first recognized as a possible new disease in Rakai District in 1982
- By the end of 1997, UNAIDS estimated that 1,800,000 Ugandans have already died with AIDS, out of a population of 20 million
- in 1997, UNAIDS estimated that 9.5% of Uganda's adults are HIV infected
- UNAIDS estimates that by 1997, over 930,000 Uganda adults and children are living with HIV

HIV/AIDS Activities in Uganda

- Gov't fully committed to AIDS prevention; ACP established in 1986
- Mulago Hospital in Kampala established AIDS clinic
- TASO established in 1988, began serving clients in 1989
- Intense HIV/AIDS education began 1988-89
- Mass media, radio, billboards common
- Intensive & extensive HIV projects since 89, implemented by NGOs and government ministries, funded by WHO, USAID, DFID, DANIDA and other donors
- AIDS education in the community, workplace, military, schools, churches and mosques, and peer education
- Multi-sectoral AIDS Commission established in 1991
- Knowledge of risk factors and high prevalence led to demand for HIV testing; The AIDS Information Centre opened in 1990

History of TASO: the 80s

- in 1986, a group of individuals and families affected by the epidemic began meeting together to offer mutual support and fellowship
- in 1986, 16 individuals, some with AIDS and some medical personnel, began sensitizing hospital staff about the needs of persons with AIDS
- ActionAid sponsored the initial workshops for mobilisation for awareness in 1986; initial ActionAid funding was given in 1987
- in 1987, The AIDS Support Organization, TASO, was incorporated as a NGO to provide care and support for persons with AIDS and their families
- in 1988, USAID began providing funds to TASO
- in 1989, TASO began serving clients in Mulago (Kampala), Masaka, Mbarara and Tororo

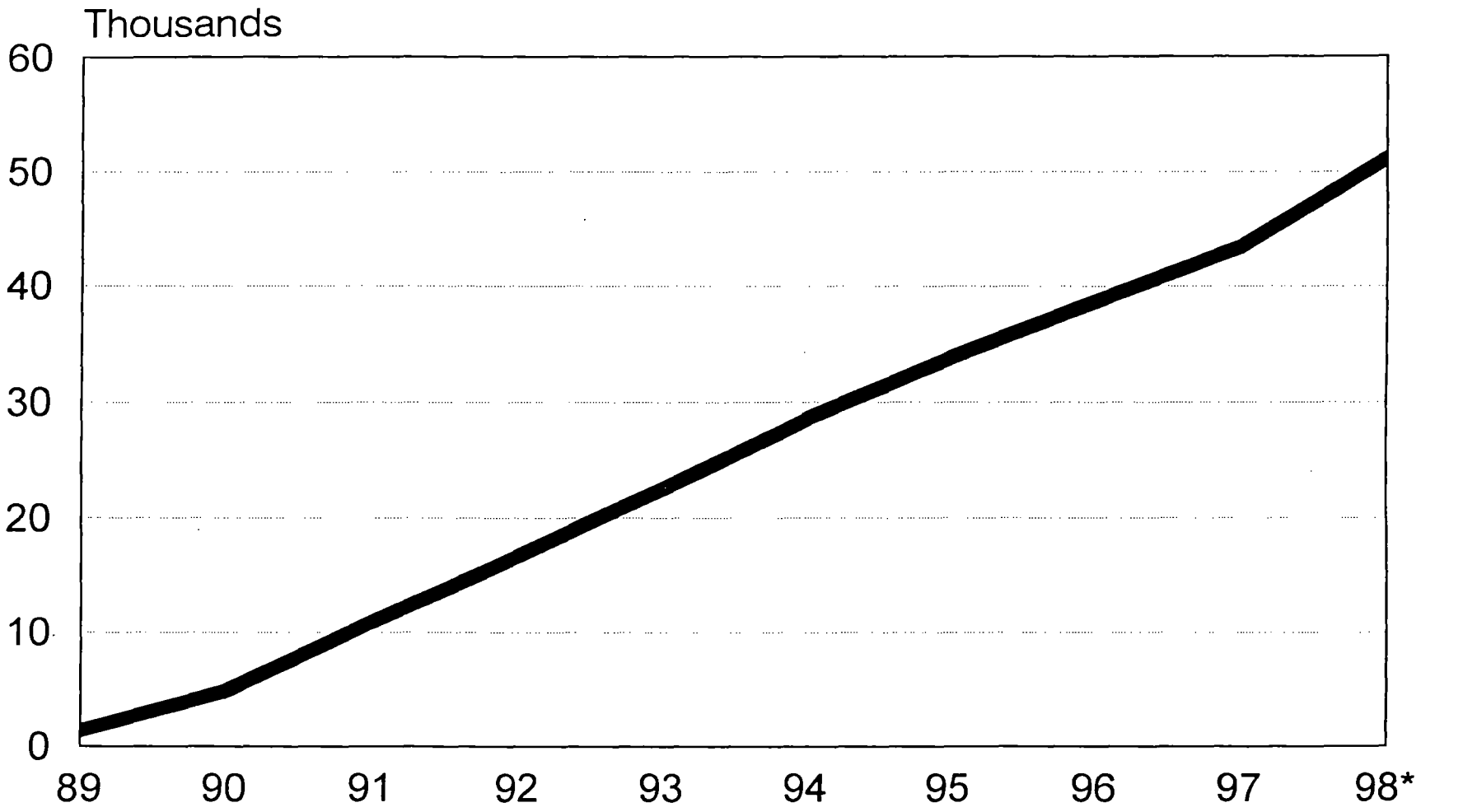
History of TASO: the early 90s

- 90: TASO receives the "It Works" award from NORAD and funding from UK gov't
- 90: TASO Mbale and Entebbe begin serving clients; TASO Jinja began organizing
- 91: large 5 year grant received from USAID through World Learning; DFID funds also began
- 91: TASO Community Initiatives begins to encourage community involvement
- 92: first group of 120 counselors graduated; DANIDA funding began
- 93: drama groups active in all centres
- 94: TASO Mbarara inaugurated by US Ambassador and UK High Commissioner
- 94: first comprehensive evaluation of TASO services; SIDA funds granted; new model of hospital based TASO services began in Arua

Primary Components of TASO Services and Activities

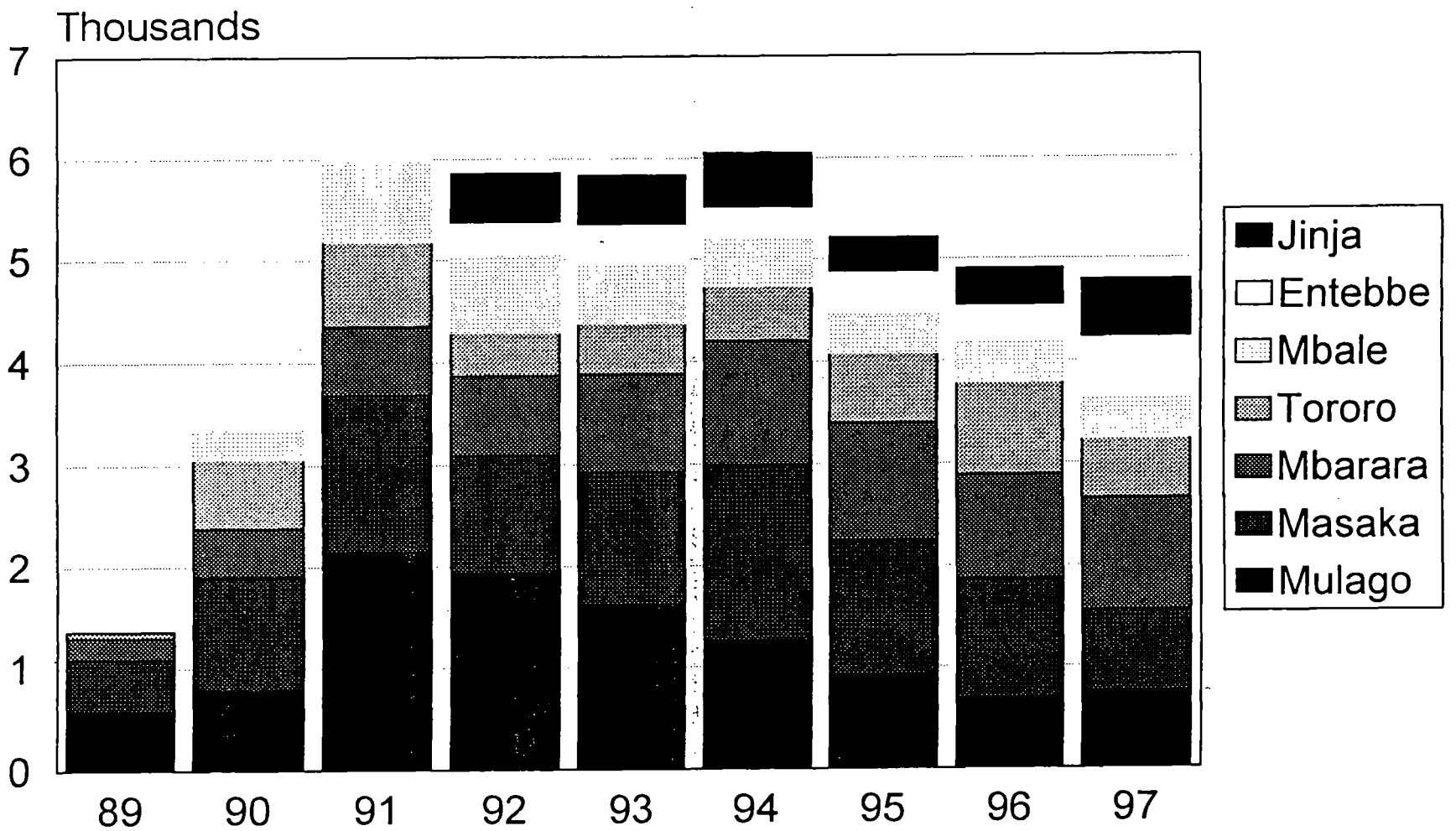
- Counseling for TASO clients and family members
- Medical care for TASO clients
- Social support provided; food, school fees, skills building for income generating activities
- AIDS education to raise awareness and decrease stigma
- Advocacy for rights of persons living with AIDS and promote responsibility
- Community mobilisation to encourage local participation in AIDS care and prevention
- Training of AIDS counselors, community workers, peer educations, medical workers
- Institutional capacity building for local groups involved in AIDS care
- High quality, consistent services which earn public trust and support

Cumulative Demand for TASO Services: Numbers of New Clients Registered

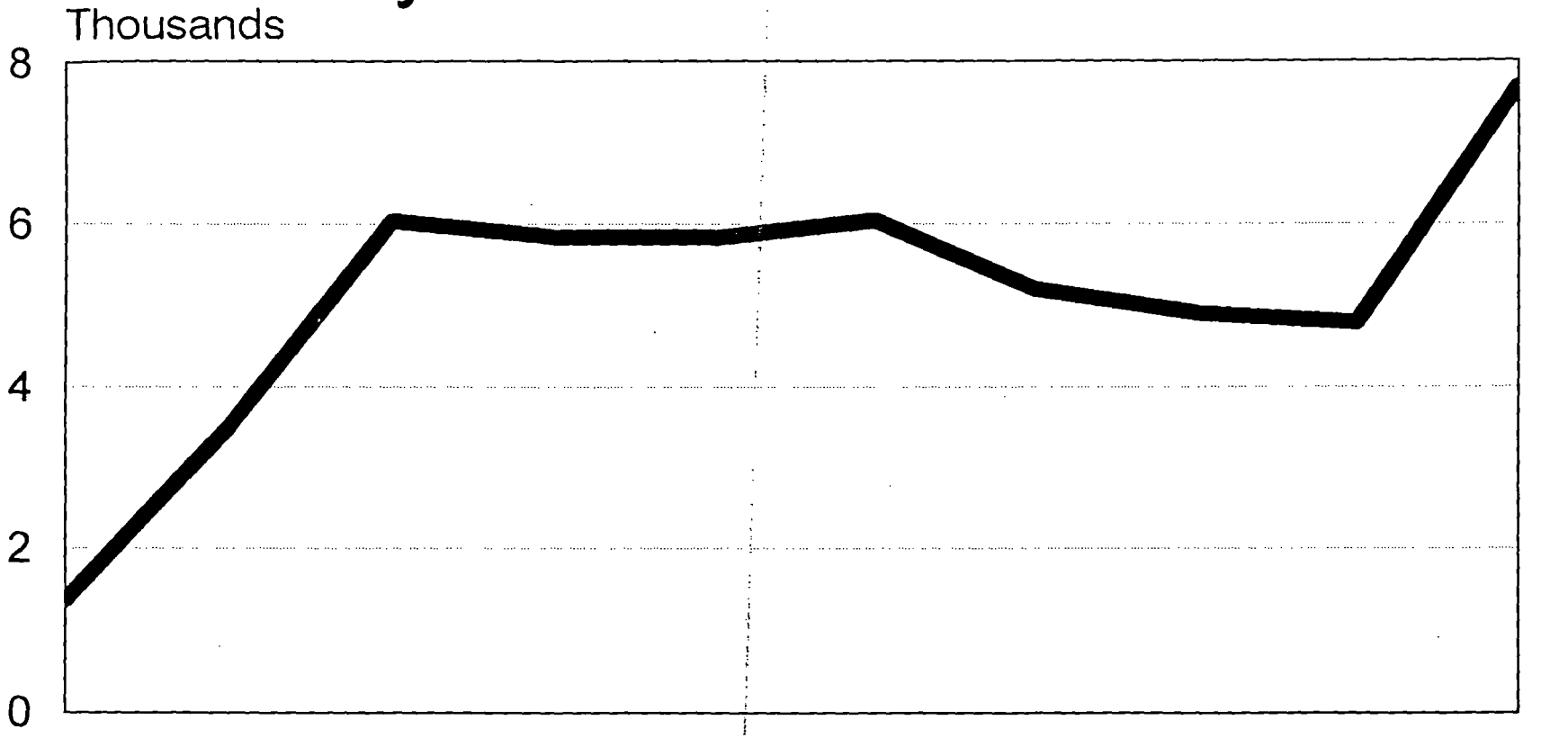


*98 projected

Distribution of TASO Clients



Annual Number of New Clients Registered by TASO: 1989 - 1998



89	90	91	92	93	94	95	96	97	98*
4	6	6	7	7	7	7	7	7	7

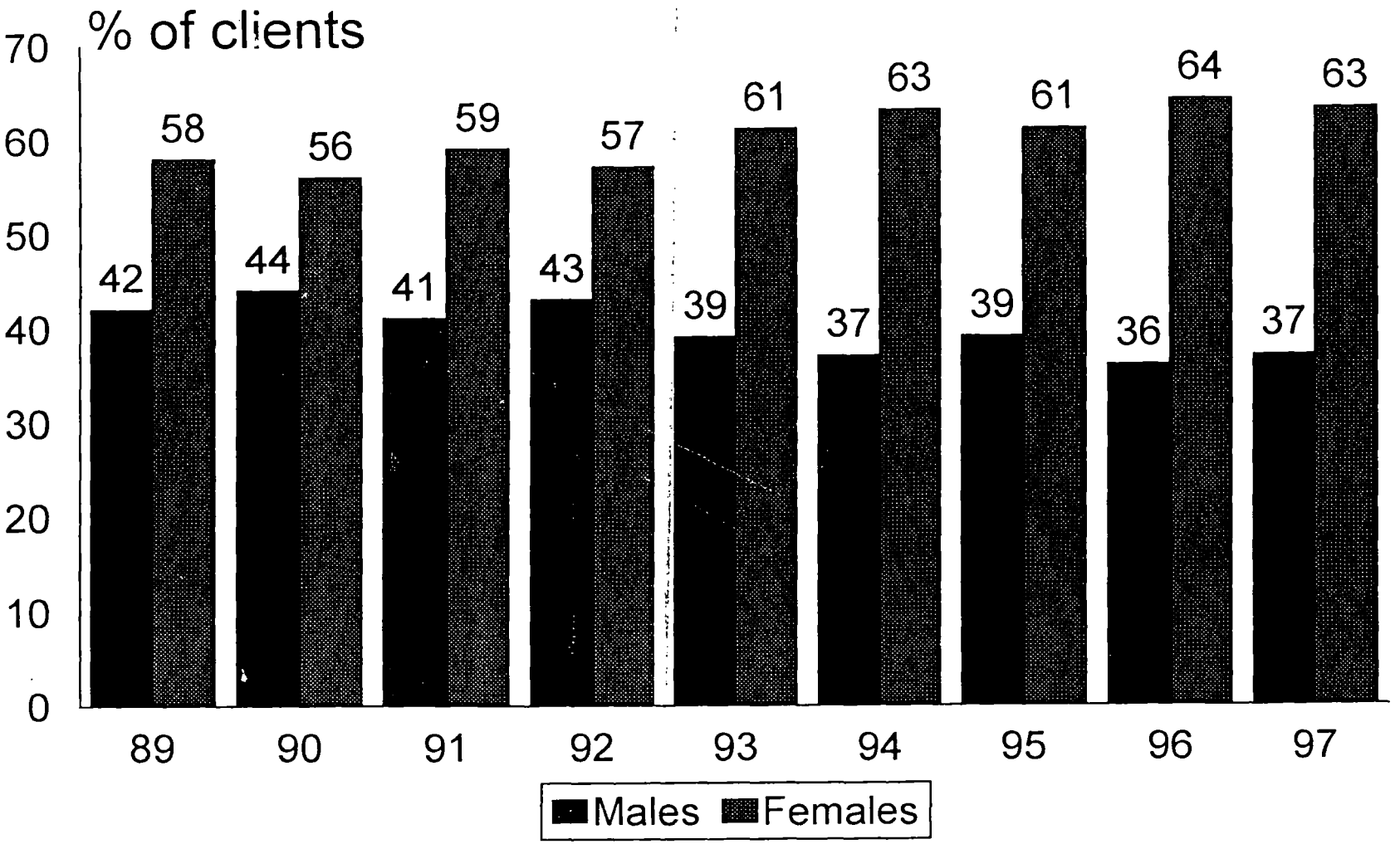
# of centres in full operation

1361	3467	6037	5837	5828	6044	5204	4901	4787	7685

# of new clients at each centre

*98 projection

TASO Clients by Gender



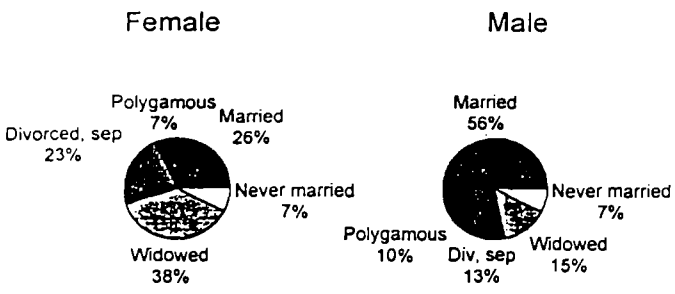
Challenges for TASO in the Future

- Maintaining community commitment and momentum for local response
- Apparent stabilisation in numbers of TASO clients not seen in 1998 with significant increase in new clients
- Trend toward increasing percentage of TASO clients being women may impact on types of services needed
- Increasing the availability of AIDS care in rural areas
- Clients' concerns about breastfeeding, mother to child transmission, access to HIV drugs
- Sustainability of TASO in the future

Lessons Learned & Conclusions

- Caring for persons living with AIDS promotes HIV prevention
- Comprehensive program including counseling, medical care, economic assistance is needed
- Integrated services for AIDS care, family planning, and STDs are feasible and beneficial
- Data-based decision making more effective
- Communities can be mobilised to share the responsibility for AIDS care and HIV prevention at the local level
- TASO clients can serve as change agents through the drama groups
- Participation of TASO clients at management level essestial
- Collaboration is critical among all stakeholders
- Personal commitment to a positive response to the AIDS epidemic is essential among TASO staff, clients, volunteers, donors and government

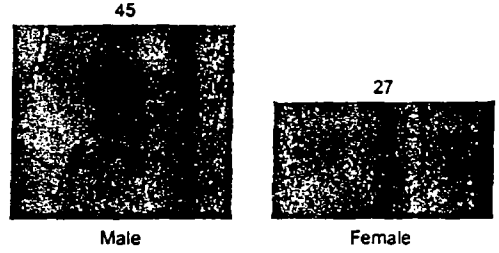
Marital Status of New Clients - 1997



66% of men are in a union, but only 33% of women

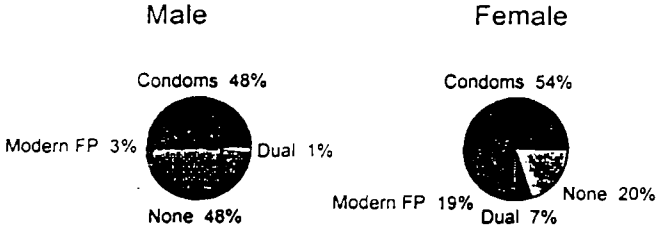
Percent of Adult TASO Clients reporting Sexual Activity

Most Clients are not sexually active



total n with data: 9129

Contraceptive Use among TASO Clients - 1997

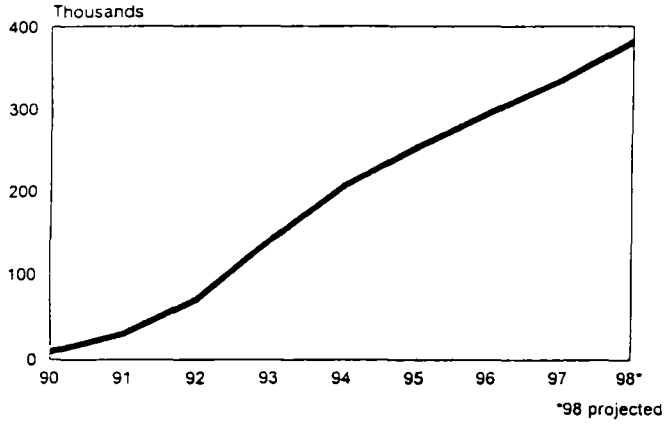


n=3000

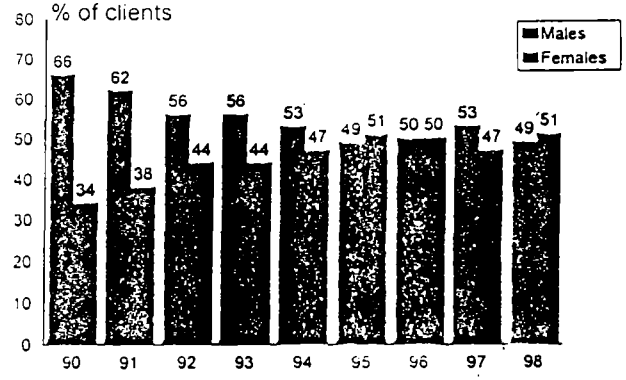
Results: Voluntary Counseling and Testing (VCT)

- USAID/Uganda supported the first site to offer voluntary counseling and testing (VCT) in Africa
- project has successfully served almost 400,000 since 1990
- other donors are now funding VCT (DFID, UNFPA, UNAIDS)
- the AIDS Information Centre (AIC) has served as site for research on effectiveness of VCT, TB preventive therapy, discordant couples, and will assist with prevention of mother to child HIV transmission projects in Uganda
- AIC has piloted the use of rapid tests for same day results
- AIC is now providing integrated reproductive health services, including family planning and STD detection and treatment
- VCT demonstrated to be feasible and well accepted by local population; model is now being replicated in other sites in Africa

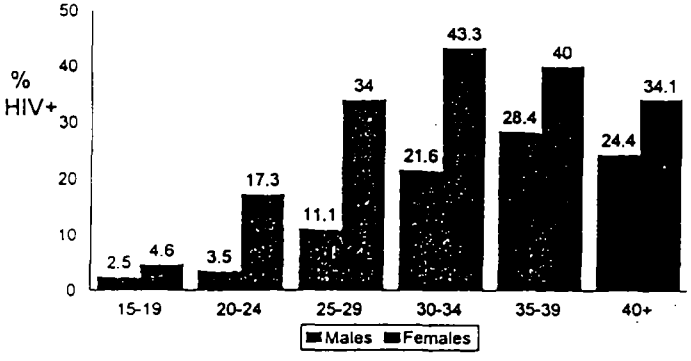
Cumulative Demand for VCT at AIC



VCT Demand by Gender at AIC

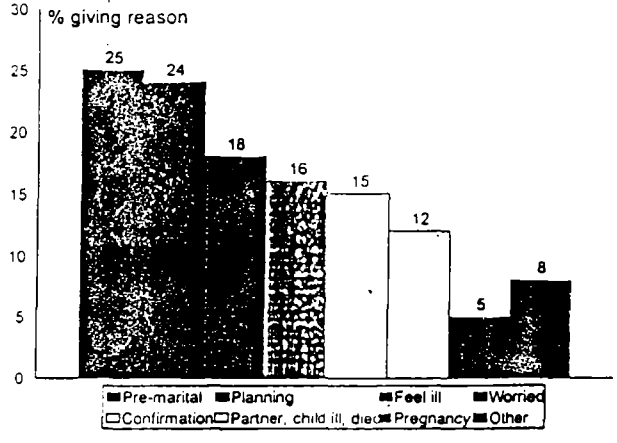


Women who request VCT in Uganda are more likely to be HIV+ than men in all ages

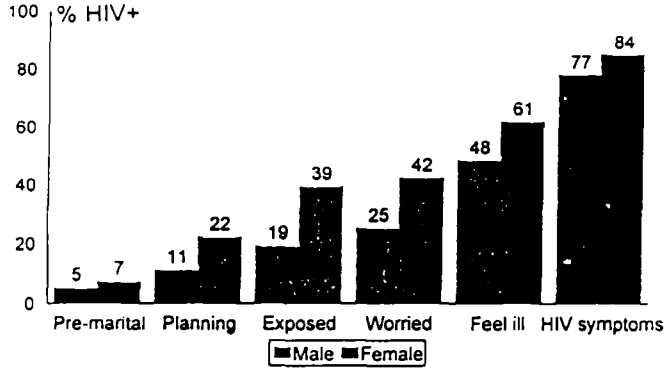


source 1997 data, the AIDS Information Centre, n=37,694

Reasons for seeking VCT, 1997



HIV rates by Reasons for Requesting VCT -- 1997

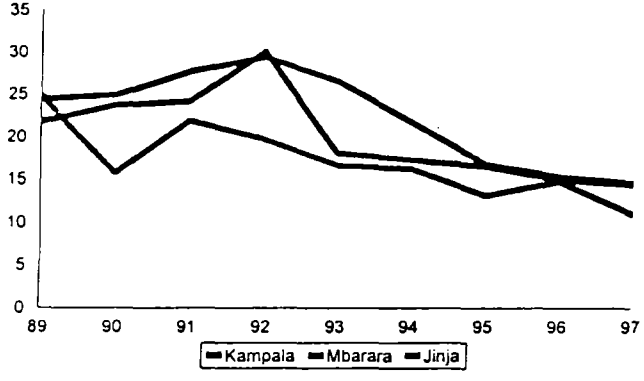


Overall Results of Uganda's Response to AIDS

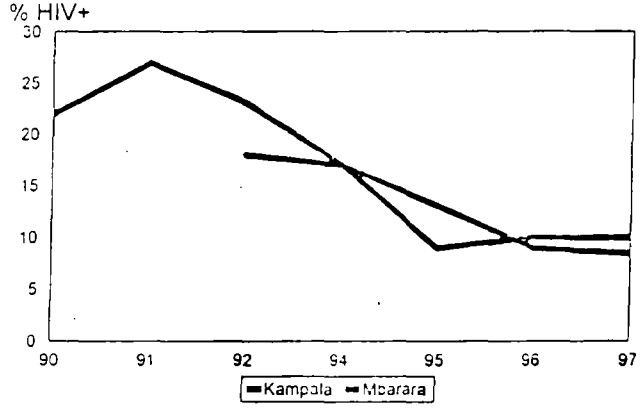
- almost 100% level of awareness of AIDS
- evidence for behavioral changes
- evidence of changing social norms, esp regarding multiple partners, condom use, pre-marital testing
- restoration of hope for the future of Uganda
- citizens have observed the power of candid and collaborative approach to national problems
- evidence of declining trends, esp in rate of new infections in young people

HIV Infection Rates in antenatal clinics in Uganda

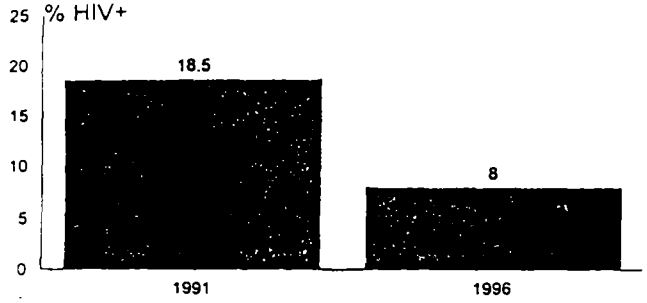
Ministry of Health Data



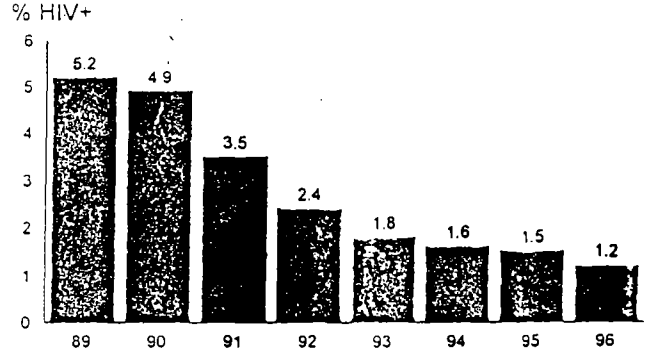
HIV Rates in 15-19 year old ANC attenders



HIV Prevalence in young men aged 19-22 entering the army (Gov't of Uganda data)



HIV Prevalence in Secondary School Blood Donors



Essential Components in Uganda's Response to AIDS

- consistent political support for AIDS interventions from the highest level
- consistent and generous donor support, esp USAID, since 1988
- PWAs have been involved in the design and implementation of projects
- PWAs, TASO, and other groups have successfully reduced stigma, discrimination, and fear of testing
- Religious groups have had active community programs and for the most part now support condom education and promotion
- well run pilot projects (AIDS care, VCT) have been sustained long after pilot phase
- interventions and local organizations have gained credibility and trust from both public and donors

Conclusion

- intense response to the AIDS epidemic can achieve measureable results
- intense & sustained collaboration between host government, non-governmental organizations, American scientists, & USG agencies (USAID, NIH, CDC) can significantly enhance a nation's response to the AIDS epidemic

U.S. Agency for
International Development
The AIDS Story in Uganda

Though AIDS was only recognized as a new disease in the United States in 1981, by 1982 Ugandan physicians began observing unexplained deaths in young adults. This mysterious wasting condition was soon called "slim," and that nickname for AIDS still sticks in Uganda today. Soon after taking over leadership of the country in 1986, President Museveni confronted the growing epidemic with candor and activism, and by the end of 1986, the Ministry of Health had established an AIDS Control Program, which began collecting data and conducting public information campaigns.

By 1988, USAID began providing assistance to Uganda and the fledgling non-governmental organizations struggling to respond to the dual needs of preventing further infections and caring for those already infected with the virus. The National Institutes of Health began providing research grants to American scientists investigating various aspects of the epidemic, including mother-to-child HIV transmission, the link between HIV and tuberculosis, and the epidemiology of AIDS in rural communities.

- This 10-year collaboration between Uganda and the United States has produced remarkable results. The AIDS Support Organization, TASO, now recognized as the premier agency in sub-Saharan Africa providing care to persons living with AIDS, was first given USAID assistance in 1988, and TASO continues to receive USAID support.

- By the end of 1997, TASO had cared for over 40,000 clients and their families and had trained hundreds of AIDS counselors in Uganda and elsewhere in Africa. TASO has also provided national leadership in reducing the stigma and discrimination typically associated with AIDS.

By 1989, it became apparent that many Ugandans were knowledgeable about AIDS and were eager to learn whether they had already been infected. In the absence of HIV counseling and testing sites, people were donating blood to learn their HIV test results, creating a serious problem for the national blood transfusion service, which was not equipped to provide intensive counseling.

- Once again, USAID responded quickly, and in February 1990, the AIDS Information Center opened, the first program in Africa offering voluntary and anonymous HIV counseling and testing.

What are the factors contributing to Uganda's remarkable success in responding to the AIDS epidemic? Perhaps most important has been the leadership provided by President Museveni, creating a national environment that encouraged the development of innovative and pioneering programs such as the AIDS Support Organization and the AIDS Information Center.

The courage shown by many people living with AIDS, who publicly talk about how they became infected, the importance of getting tested, and how they "live positively" with AIDS, has made a dramatic and emotionally compelling key to the success of HIV prevention programs. The commitment and professional competence of Ugandan public health workers, AIDS educators and activists, and health care workers has helped these programs achieve successful results. Finally, the early, intense and sustained level of USAID assistance given to these Ugandan partners has enabled them to achieve a first in Africa: a decline in new HIV infections in young people.

Uganda's Response to the AIDS Epidemic and Current Trends

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Government of Uganda Response

- President Museveni spoke openly and widely about AIDS as early as 1986
- AIDS Control Programme established in 1986; educational programs, mass media and blood safety efforts began
- Intense public information efforts have continued to the present
- International AIDS researchers encouraged to work in Uganda; President Museveni requests vaccine trials
- 1991: multisectoral Uganda AIDS Commission established

Response of Non-Governmental Organizations

- Mission hospitals began AIDS care programs
- The AIDS Support Organization(TASO) established in 1987 by 16 Ugandans affected by the epidemic
- The AIDS Information Centre (AIC) began providing HIV counseling and testing in 1990
- Numerous smaller NGOs established to provide care to persons with AIDS and support for orphans
- Associations of PWAs (People with AIDS) organized for education, mutual support

Response of Religious Communities

- with USAID funding, Church of Uganda (Protestant) and the Islamic Medical Association of Uganda initiated active programs of AIDS education for religious leaders and lay workers at the community and parish level
- Catholic church active in AIDS care and orphans programs

Response of the USG

- NIH funding for numerous research projects
- CDC technical assistance; research in variant strains, health information systems, and evaluation of interventions
- since 1988, USAID has provided very generous and sustained funding for multi-faceted, intense and extensive AIDS prevention activities
- USAID funding for AIDS activities has now exceeded $40 million

Response of U.S. Universities

- US Universities active in Uganda include Case Western Reserve University, Columbia University, Johns Hopkins Univ
- with NIH funding, long term biomedical research projects began in 1988 in the areas of:
  - pediatric AIDS
  - mother to child transmission
  - HIV and TB
  - community epidemiology
  - STDs, Kaposi's sarcoma & HIV
  - Vitamin A for HIV+ children
  - preparation for AIDS vaccine trials
  - social and anthropological aspects of the epidemic

USAID funded Activities

- AIDS education in the workplace, military, local communities, religious groups
- professionally designed information and education campaigns through mass media and local level IEC activities
- condom promotion and distribution
- HIV counseling and testing
- AIDS care and support
- detection and treatment of other STDs
- capacity building and technical training

Results of USG supported efforts

- greater understanding of the epidemic in Africa, esp in the area of HIV/TB and mother to child transmission
- application of therapeutic interventions in Africa-- trials of short course AZT during delivery, HIVIG, preventive TB therapy, vaccine trials, mass STD treatment
- behavioral impact of interventions documented, esp for HIV CT and community education
- Hundreds of Ugandan scientists, physicians, social workers, health educators, and program managers have been trained and developed skills
- feasibility of projects demonstrated
  - community education, esp with religious groups
  - increased acceptance, use, and sales of condoms
  - AIDS care and support
  - voluntary counseling and testing

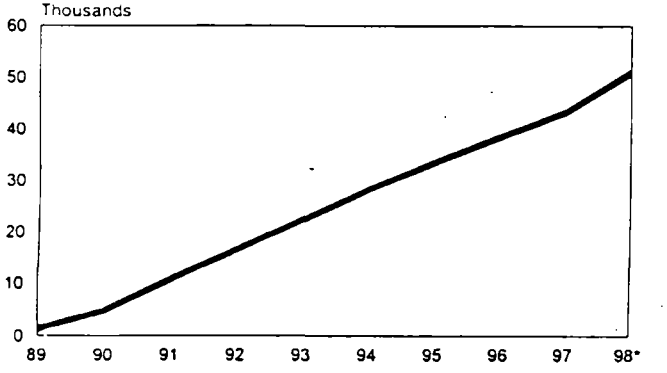
Results: Community Education through Religious Groups

- over 2,000 religious leaders trained
- over 14,000 community workers and volunteers trained
- over 1.6 million documented contacts with individuals and families
- decrease in multiple and/or casual partners reported by those reached by the projects
- increase in condom acceptance and use

Results: AIDS Care and Support

- through TASO, The AIDS Support Organization, over 50,000 persons living with AIDS given care and support
- TASO has also trained over 600 AIDS counselors and thousands of local volunteers
- a model of AIDS care and counseling developed which is being replicated throughout Uganda and throughout Africa

Cumulative Demand for TASO Services: Numbers of New Clients Registered



TASO Clients by Gender