

Journey of 09 Years of Financial Assistance Scheme of Delhi Government for Orphan Vulnerable Children Affected by HIV/AIDS-Implementation Challenges and Strengthening Initiatives

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Abstract

Delhi State AIDS Control Society (DSACS) has been implementing the first Government supported cash transfer scheme of the country for people living with HIV/AIDS (PLHIV) and orphan vulnerable children (OVC) infected or affected by HIV/AIDS in Delhi for the last 9 years to support access to health services, nutrition, and improve adherence to anti-retroviral treatment (ART). The scheme is based on certain eligibility conditions which the beneficiary must satisfy for enrollment and subsequent continuance of the scheme. Accordingly, beneficiaries were classified into four categories, namely, 1, PLHIV including children on ART; 2, double orphan children infected with HIV/AIDS (double OCI); 3, destitute children infected with HIV/AIDS (DCI) in institutional care; and 4, double orphan children affected by HIV/AIDS (CABA) in community-based care in Delhi. During 1st April 2012 to 31st March 2021, cumulative 5257 beneficiaries were prospectively enrolled for cash transfers, including 5150 PLHIV, 32 double OCI, 49 DCI, and 26 double orphan CABA. There is five-fold growth in number of beneficiaries during 9 years of its implementation from baseline 1110 (PLHIV-1083, AIDS orphan-27) enrolled during 2012-13. During follow-up, 291 (5.53%) beneficiaries expired, including 270 (5.6%) adult PLHIV, 12 (3.62%) CLHIV, 8 (25%) double OCI, and 1 (2.04%) DCI. Further, 253 (4.8%) beneficiaries became non eligible for cash transfers on account of migration (n = 102), opted out ART/or lost to follow-up (n = 119), 11 double orphan CABA attained age of 18 years, and 21 PLHIV became non eligible on income criteria. Also, 29 double OCI/DCI who accomplished age of 18 years were switched to category I for lifelong financial assistance. Though identification and enrollment of beneficiaries has been slow, adherence to ART is good (> 95%) in majority. DSACS has taken several initiatives to strengthen scheme including relaxing eligibility criteria and enhancing quantum of financial assistance due to rise in Cost Inflation Index. However, monitoring of the scheme is a challenge and impact assessment needs to be carried out.

Keywords: Cash Transfers; Orphan Vulnerable Children (OVC); People Living with HIV/AIDS (PLHIV); Children Affected by AIDS (CABA); Social Protection

Introduction

It is currently estimated that India has about 2.3 million people living with HIV (PLHIV), with an adult (15 - 49 years) HIV prevalence of 0.22%. Children living with HIV (CLHIV) comprise 3.4% of total estimates. Adult HIV prevalence of Delhi is 0.41%, which is higher than national average [1]. In Delhi since 2004, total 70,174 adults and 3,174 children have been registered in HIV care; 49,445 adults and 2,285 children were initiated antiretroviral treatment (ART); and currently 30,496 adults and 1,590 children are alive on ART. AIDS mortality rate of 5.21 per 100,000 population in Delhi is higher than national estimates of 4.43 per 100,000 population [1]. Since 2004, total 6977 (14%) adults and 313 (13.7%) children started ART in Delhi have died, while the number of deaths in those initiated ART but lost to follow up (LFU) or not initiated ART and subsequently LFU is unknown. From experience of high HIV burden regions, it is known that AIDS related deaths produce significant socioeconomic impact on affected families leaving affected children as orphan and vulnerable due to lack of proper nutrition, education, health care and social protection [2,3]. Social cash transfer programs globally have shown positive impact on livelihood, nutrition, school enrollment, accessing health services and adherence to Anti-Retroviral Treatment in affected orphan vulnerable children [4-11].

Taking lead in the country, Government of Delhi analyzed the situation of orphan vulnerable children (OVC) infected or affected by HIV/AIDS in Delhi in 2010 that enabled development and launch of this first state government sponsored cash transfer scheme for OVC Infected or Affected by HIV/AIDS on 1st April 2012 on principle of household economic strengthening of PLHIV with aim to support travel cost to access health services, nutrition, educational material, skill building and improve adherence to anti-retroviral treatment (ART). The salient features of the scheme were published in Vulnerable Children and Youth Studies in 2013 [12].

National AIDS Control Organization (NACO), Government of India recognized this initiative as a best practice in the country and helped publicize the idea nation-wide and South Asia. On recommendation of NACO, one of the authors (Dr. AKG) presented features of the scheme during 'Consultative Meeting to Review Achievements and Progress on Protection, Care, and Support for Children Affected by HIV and AIDS in South Asia' held in Kathmandu in September 2013 [13]. Over the years, DSACS received Annual Grant-in-Aid (GIA) from Health Department, Delhi Government regularly to implement the scheme. This communication presents achievements of the scheme, implementation challenges and strengthening initiatives.

Materials and Methods

The cash transfer scheme was approved by Delhi Government for implementation from 1st April 2012. Various eligibility conditions for cash transfers, process for identifying cases, method of payments to beneficiaries, and ways to prevent corruption were defined as part of standard operative procedures for the scheme [12]. The scheme is based on certain eligibility conditions which the beneficiary must satisfy for enrollment as well as subsequent continuance of scheme. Accordingly beneficiaries were classified into four categories, each with different eligibility criteria and amount of financial assistance viz; category 1, PLHIV including children on ART in Delhi; category 2, double orphan children infected with HIV/AIDS (double OCI) in community-based care in Delhi; category 3, destitute children infected with HIV/AIDS (DCI) in institutional care in Delhi; and category 4, HIV negative double orphan children affected by HIV/AIDS (CABA) in community-based care in Delhi; with monthly financial assistance of INR 1000 (≈USD 13.7 @ INR 73/USD); INR 2050 (≈USD 28); INR 2050 (≈USD 28) and INR 1750 (≈USD 24), respectively.

For enrollment, category 1 beneficiary should be on regular ART for last one-year, resident of Delhi for last three-years, and annual family income from all sources should be ≤ INR 1,00,000 (USD 1369). At least one parent of double orphan in category 2 and 4 should have died of HIV/AIDS. Destitute children in institutional care should be on ART of any duration in Delhi. There was no restriction on number of beneficiaries in a family. The guardians/caregivers/institution was required to spend the amount received for care of the child only. The financial assistance to double orphan was in addition to any other financial assistance to them by government. The financial assistance to category 1 beneficiaries was for life long.

For continuity of cash transfers, the ART Clinics/Institutions were required to submit life certificate of beneficiaries to Delhi State AIDS Control Society (DSACS), the implementing agency, every three months, that they were alive and > 95% adherent to ART, failing which cash transfers were stopped. On attaining 18 years' age, double OCI/DCI would be switched over to category I for lifelong financial assistance. However, benefit to CABA would end at 18 years of age.

To implement the scheme, 11 government ART clinics of Delhi were instructed to identify eligible beneficiaries, collect their applications and essential documents like residence proof, income proof from Revenue Department, HIV test/treatment reports, parental death certificates; bank details etc. to be forwarded to DSACS for evaluation by State Screening Committee (SSC) consisting of government experts from different departments. Upon recommendation of SSC category wise beneficiaries were enrolled for cash transfer scheme. The financial assistance was planned to be transferred directly into bank account of beneficiaries by electronic transfer every month through nationalized bank by accounts officer of DSACS.

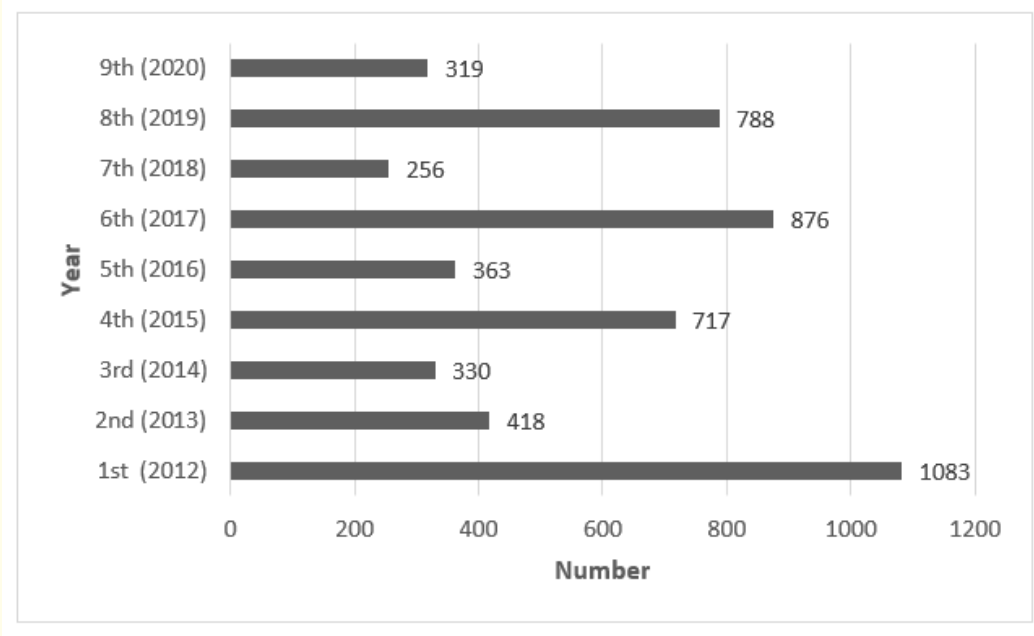
As executing organization, DSACS was directed to develop an appropriate mechanism for monitoring of scheme, follow-up of beneficiaries and ensure that advantage of scheme extends to eligible beneficiaries. Since June 2016, DSACS is using Public Financial Management System (PFMS), a web-based online software application developed by Controller General of Accounts Department of Ministry of Finance, Government of India for Aadhaar Number (AN) based Direct Bank Transfers (DBT) to ensure greater transparency and accountability and improve program and financial management [14]. Due to low uptake of beneficiaries, DSACS moved proposal on 31st August 2018 for approval of Delhi Government to relax some eligibility conditions and enhance amount of financial assistance because of rise of cost inflation index year by year due to inflation. Meeting of Cabinet of Ministers was held on 6th December 2019 on order of Delhi High Court in response to Public Interest Litigation by a PLHIV beneficiary on 28th April 2017 to release timely payments to beneficiaries by a pre-defined date every month.

For gap analysis of the scheme, ART program data of Delhi for period from 1st April 2012 to 31st March 2021, managed by DSACS on Computerized Management Information System (CMIS), a web-based application of National AIDS Control Organization (NACO), Government of India, was evaluated for current number of PLHIV alive on ART, died or LFU vis-a-vis the current coverage of cash transfer scheme. ART adherence rates for month of March 2021 on a sample of PLHIV on ART were evaluated. Present status of DCI in institutional care at NGO Naz Foundation, Siam New Generation Trust and Deepti Foundation was obtained from respective Project Managers.

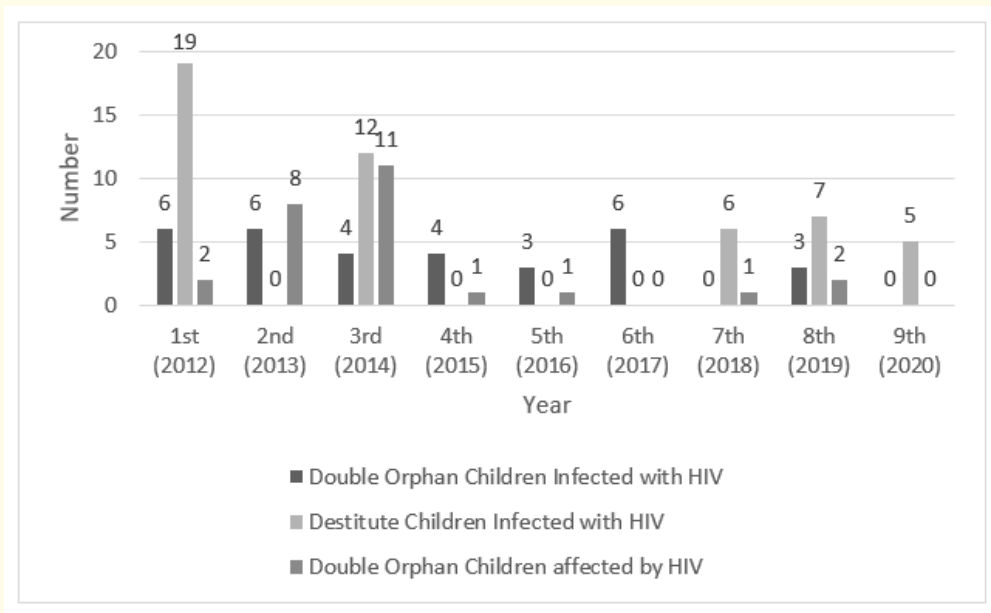
Results and Discussion

Achievements of cash transfer scheme

During 1st April 2012 to 31st March 2021, cumulative 5257 beneficiaries were prospectively enrolled for cash transfers, including 5150 PLHIV (4819 adults, 331 children), 32 double OCI living under care of grandparent/elder sibling/extended family, 49 destitute children in institutional care (DCI), and 26 double orphan CABA in community-based care in Delhi. There has been about five-fold growth in number of beneficiaries during 9 years of its implementation from baseline 1110 (PLHIV-1083, AIDS orphan-27) beneficiaries enrolled in first year of scheme. However, Year-Over-Year (Y-O-Y) enrolment of category 1 (PLHIV) and category 2 - 4 (AIDS Orphan/destitute children) beneficiaries displayed in bar graph 1 and 2, respectively, shows that the highest number of beneficiaries were enrolled initially, thereafter no. of cases enrolled remained poor despite revision in ART guidelines in May 2017 to 'Treat all PLHIV Irrespective of Clinical Stage or CD4 count' [15] when more number of PLHIV (Category 1 beneficiary) were expected to be eligible for scheme on completing one year of ART.



Bar Graph 1: Showing year-over-year number of PLHIV enrolled for cash transfer scheme (N = 5150).



Bar Graph 2: Showing Y-O-Y enrolment of AIDS orphan/destitute children (N = 107).

On excluding category 4 beneficiaries (HIV negative), 5231 beneficiaries [including PLHIV and orphan/destitute CLHIV] were on regular ART as confirmed by DSACS from ART clinics every 3 months and hence cash transfers were continued, except in those who eventually either died, migrated, opted out ART or lost to follow up (LFU). During 9 years follow-up (Box 1), 291 (5.53%) beneficiaries expired including 270 (5.6%) adult PLHIV, 12 (3.62%) CLHIV, 8 (25%) double OCI, and 1 (2.04%) DCI. Further, 253 (4.8%) beneficiaries became non eligible for cash transfers on account of migration (n = 102), opted out ART/or LFU (n = 119), double orphan CABA attaining 18 years of age (n = 11), and 21 PLHIV became non eligible on income criteria. Also, in 29 double OCI/DCI who accomplished age of 18 years, the cash transfers were switched over to Category I for lifelong financial assistance.

Cumulative Enrolment -	5257
(a) Adults PLHIV	4819
(b) Children	438
-CLHIV	331
- Double Orphan Children Infected with HIV/AIDS	32
- Destitute Children Infected with HIV/AIDS	49
- Double Orphan Children Affected by AIDS	26
Expired -	291
(c) Adults (PLHIV)-	270
(d) Children	21
-CLHIV	12
- Double Orphan Children Infected with HIV/AIDS	08
- Destitute Children Infected with HIV/AIDS	01
Switch to Category I on attaining age of 18 years	29
(a) Double orphan children Infected by HIV/AIDS	11
(b) Destitute children Infected with HIV/AIDS	18
Beneficiaries Turning Out Not Eligible	253
(a) PLHIV annual family income > INR 1,00,000	21
(b) Adult PLHIV opted out ART/LFU-	97
(c) CLHIV opted out ART/LFU-	17
(d) PLHIV Migrated/ Transfer out of Delhi for ART-	102
(e) Double orphan children Infected with HIV/AIDS opted out ART/LFU-	05
(f) Double orphan CABA attaining age of 18 yrs.	11
Current Beneficiaries:	4713
(a) Adults (PLHIV)-	4358
(b) Children:	355
-CLHIV	302
-Double orphan children infected with HIV/AIDS	08
-Destitute children infected with HIV/AIDS	30
-HIV negative Double orphan CABA	15

Box 1: Follow-up data (1st April 2012 to 31st March 2021).

Currently, 4713 beneficiaries, including 355 children are availing benefit of scheme. This includes 4358 adult PLHIV and 302 CLHIV, 8 double OCI, 30 DCI in institutional care at Non-Government Organizations and 15 double orphan CABA in community-based care. After excluding those who died, migrated, discontinued scheme on income criteria or opted out ART, the ART adherence was reported good ($\geq 95\%$) in 4696 (97.5%) beneficiaries. This ART adherence in beneficiaries of scheme is higher than overall adherence reported by 11 ART clinics in last monthly survey in March 2021, where 19595 (91.8%) of sample of 21338 PLHIV on ART surveyed showed good ($\geq 95\%$), 1179 (5.6%) had average (80-95%) while 564 (2.6%) had poor ($< 80\%$) adherence.

Implementation challenges and strengthening initiatives

Low uptake of the beneficiaries

People Living with HIV/AIDS

At present only 14.3% (n = 4358) of 30,496 adults and 19% (n = 302) of 1590 children living with HIV/AIDS alive on ART in Delhi are getting benefit of the scheme, whereas it is estimated that 35 - 40% of PLHIV may need financial assistance.

The low uptake of beneficiaries for scheme may be due to first; uncaring attitude of some counsellors of ART clinics where potential beneficiaries need to be informed, screened for eligibility, and enrolled for the scheme; second, beneficiaries face difficulty in obtaining income proof from Revenue Department at time of enrollment for scheme; and third, payment is stopped in some beneficiaries subsequently when their income increased $> \text{INR } 1,00,000$ or if they failed to submit subsequent income proof every 6 months or if they didn't provide quarterly regular treatment certificate from ART clinics.

ART clinics have been instructed to screen all PLHIV reporting for treatment for eligibility of scheme and facilitate their enrollment. From August 2018, eligibility criteria for continuation of scheme have been modified by Delhi Government; first, income proof from Revenue Department will continue to be mandatory for enrollment to scheme, but subsequently only undertaking of the beneficiary will suffice; second, regular treatment certificate of PLHIV will be based on biometric attendance machines on quarterly basis. However, if the beneficiary is sick or bed ridden or any other justifiable reason, a relative or friend may be allowed to collect ARV medicines for that month only and beneficiary must visit ART clinic in subsequent months. Special provision has been kept for verification of regularity of treatment by Nodal Officer of ART clinic.

AIDS orphans/DCI in institutional care

Currently, only 8 double OCI, 30 DCI in institutional care and 15 double orphan CABA in community-based care are enrolled for the scheme.

Low enrollment of AIDS orphans may be due to first; complex documentation, such as proof of death of both parents and that at least 1 parent died of HIV/AIDS; second, lack of proper counselling and education of caregivers and affected families about scheme at ART clinics; third, lack of family centric approach of ART clinics with predominantly ART focused service with eventual lack of mechanism to identify and track orphan children in case PLHIV registered in HIV care expire. Hence, actual magnitude of HIV/AIDS Orphans remain unknown.

Further, with limited number of NGOs providing institutional care to destitute HIV infected children in Delhi, it looks straightforward to identify such children. However, at present only 30 (62.5%) out of 48 DCI available have been enrolled their children for scheme as 1 of the 3 organizations, namely, Deepti Foundation, was unaware of the scheme although their children were receiving ART, but ART counselor did not try to educate and enroll the neediest due to utter carelessness.

During 2010 - 2012, DSACS did a mapping study on the number of OVC infected or affected by HIV/AIDS in Delhi and identified 203 single orphan CABA (29 HIV infected, 174 HIV uninfected), 33 double OCI, 25 DCI in institutional care and 22 double orphan CABA [12]. Bar graph 2 shows Y-O-Y registration of AIDS orphan/destitute children for the scheme. As evident, total 107 AIDS orphan/destitute children (32 double OCI, 49 DCI, 26 double orphan CABA) were registered during 9 years of scheme. However, since no large-scale community-based survey has been undertaken to determine the true magnitude of orphanhood due to HIV/AIDS in Delhi, exact number of AIDS orphan/destitute children is unknown.

ART data may provide a clue regarding number of AIDS orphans in Delhi. During April 2004 to March 2021, out of total 70,337 adult PLHIV registered in HIV care, 6977 (9.9%) died and 12082 (17%) were permanent LFU. Several LFU clients may have also died over the years without treatment. Further, evaluation of most recent ART data revealed that 36 (2.2%) of 1664 adult PLHIV initiated ART during 1st April 2020 to 31st March 2021 died and 117 (7%) were LFU. In a study at an ART clinic of Delhi, it was observed that out of 148 children on ART about 49.3% were orphan, mostly single (paternal) orphan [16]. This shows that present coverage of orphan children infected or affected by AIDS may be low.

Therefore, it has been decided in August 2018 that double orphan children infected with HIV/AIDS will be registered for the scheme irrespective of his/her parental HIV status i.e. the previous criteria that 'at least 1 parent should have died of HIV/AIDS' has been removed. Further, ART clinics need to develop some mechanism to track affected families in case of death of PLHIV to consider affected children for financial support through scheme.

However, few weaknesses of present scheme regarding OVC infected or affected by HIV/AIDS still need to be addressed, viz; (1) single orphan CABA need more focus, which is lacking in present scheme in that; first, HIV infected single orphan children are currently covered in category 1 with financial assistance equal to that of CLHIV under parental care whereas they need more amount of cash transfers and; second, single orphan children affected by AIDS are not eligible for scheme despite many of them being paternal orphan. Out of 174 single orphan CABA identified in Delhi in 2012, 144 (82.7%) were paternal orphan [12] and hence single orphan CABA should also be given financial support like double orphan CABA as mothers are mostly housewives and jobless. (2) The criteria of HIV positive children to be on ART for 01 year before inclusion in Category 1 of scheme need to be changed to 'ART of any duration' as without ART children have high mortality [8] and it may not be sensible to wait for 01 year on ART to start benefit of cash transfers meant to improve ART adherence.

Amount of disbursement is low considering cost of inflation over the years

In-spite of being provided financial assistance, most of the beneficiaries had grievance that the amount of disbursement is low considering the cost of inflation over the years. Hence, Delhi Government decided to double the amount of financial assistance from August 2018 for each of the four categories of beneficiaries and the amount will be increased annually by indexation to inflation capped at 5% per annum.

Delay in release of payment to beneficiaries

Presently, beneficiaries visit the ART clinic quarterly for stable patients and monthly for new or unstable patients and certificate in this regard is sent to DSACS from ART clinic on quarterly basis. Thereafter the certificates are entered into records after checking eligibility initiating the process of getting sanction for payment and thereafter the payment is disbursed to beneficiary through PFMS. Also, at present the scheme is managed by existing staff of DSACS and no additional manpower was provided. This results into delays in payments, payment being released only on quarterly basis, more procedural delays in checking eligibility and a burden on staff checking the eligibility.

Hence Government of Delhi decided in January 2019 to release payment to beneficiaries automatically by 10th of every month without waiting for certificate of having attended ART clinic subject to review of the regularity of the treatment of the beneficiary on quarterly

basis. In case beneficiary is found not meeting the eligibility for financial assistance such as not adhering to regular treatment i.e. not reporting to ART clinic, LFU or migrated or death or non-submission of required undertaking regarding income, release of further financial assistance shall be kept in abeyance and will be revoked only as per existing provisions of the scheme. No recovery shall be made from beneficiary/family of beneficiary for payments made under the scheme as per above provision in case beneficiary is found ineligible at time of quarterly screening or reasons such as death during the quarter or ineligibility due to any other reason. Also, to strengthen implementation and monitoring of the scheme, Delhi Government has sanctioned additional manpower consisting of one assistant programme manager and two divisional assistants with provision to be increased subsequently @ 1 divisional assistant: 2000 beneficiaries of the scheme.

Monitoring and impact assessment of scheme

Monitoring was envisaged for categories 1 - 3 beneficiaries through their ART clinic attendance for medicine pick up, whereas beneficiaries in category 4 were to be monitored by home visits by officials of DSACS. However, other than numerical data of progress of scheme, no qualitative information on impact assessment of the scheme is available.

MPH students at Boston University School of Public Health, USA established a monitoring and evaluation (M and E) mechanism for cash transfer scheme of DSACS under IH744 project in June 2014 utilizing the "CommCare" mobile health (mHealth) platform for use of DSACS and ART clinic staff to determine what funds provided through the governments conditional cash transfer scheme were being used for [17]. A logic model was developed. DSACS and ART clinic staff will administer questionnaires to the beneficiaries of the scheme on a quarterly basis. The M and E of the scheme through this program may help DSACS ensure that purchases are made on transportation, nutrition, skill-building, and health-related activities.

However, Delhi Government introduced Aadhaar Number (AN) based Direct Bank Transfers (DBT) in August 2018 to ensure that cash transfers are made only to genuine beneficiary. Also, a system of de-enrolment has been introduced by Delhi Government wherein beneficiaries will be de-enrolled in case of death, emigration out of Delhi/or transfer out for ART to other state, LFU or irregularity in treatment defined as beneficiary not attending ART clinic for getting medicine/treatment continuously for 3 months. Currently other than regular ART clinic attendance, deaths/migration, no other M&E system is in place. Like done in other countries, third party evaluation may be useful for impact assessment of cash transfer scheme of Delhi Government [3,4,7,8,11].

Conclusion

DSACS is implementing the first government supported cash transfer scheme for people living with HIV/AIDS and OVC infected or affected by AIDS in Delhi. The scheme has completed 9 years and continuing. Though identification and enrollment of beneficiaries is slow, adherence to ART is good (> 95%) in majority of the beneficiaries. DSACS has taken several initiatives to strengthen the scheme from time to time including relaxing eligibility conditions and enhancing the amount of financial assistance due to rise in inflation. However, monitoring of the scheme is a challenge and impact assessment of the scheme needs to be carried out.

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Declaration of Interest Statement

No conflict of interest.

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