

Research Report

Boston University OVC-CARE Project

DISCLOSURE OF CHILDREN'S HIV STATUS IN FOUR HIGH PREVALENCE STATES IN INDIA

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Acronyms

AAP	American Academy of Pediatrics
AIDS	Acquired Immuno Deficiency Syndrome
ART	Antiretroviral Therapy
BU	Boston University
BUMC	Boston University Medical Center
CABA	Children Affected By HIV/AIDS
CCDT	Committed Communities Development Trust
CGHD	Center for Global Health and Development at Boston University
CHES	Community Health Education Society
CLHIV	Children living with HIV/AIDS
CRS	Catholic Relief Services
HIV	Human Immunodeficiency Virus
ICTC	Integrated Counseling and Testing Centers
IRB	Institutional Review Board
MTCT	Mother to Child Transmission
NACO	National AIDS Control Organization
NACP	National AIDS Control Program
NGO	Non-Government Organization
OVC	Orphans and Vulnerable Children
PEPFAR	President’s Emergency Plan for AIDS Relief
SACS	State AIDS Control Societies
SCT	Sneha Charitable Trust
SDQ	Strengths and Difficulties Questionnaire
USAID	United States Agency for International Development
WAG-CHELSEA	Women’s Action Group: Children, Health, Education, Ladies, Senior Citizens, Environment and Awareness
WHO	World Health Organization

EXECUTIVE SUMMARY

Telling a child they are HIV positive, answering their questions about medicines, visits to the hospital and their future is a challenging and sensitive issue for parents, health care workers and HIV counseling and testing centers. India currently has the third largest number of people living with HIV in the world,¹ including an estimated 100,000 HIV positive children, many of whom are orphans.² In 2006, free pediatric ART was introduced in India. Improved access to treatment increasingly allows children living with HIV to reach adolescence and adulthood. This represented a turning point for programming for children living with, and affected by, HIV of which disclosure to children is a key component.

This report responds to the scarcity of research and programmatic knowledge on disclosure of HIV status to children in India. A study was conducted with four NGOs in Bangalore, Chennai, Delhi and Mumbai that have developed resources, models and expertise to facilitate disclosure to OVC and their families. For the purposes of the study, “disclosure” is defined as telling a child their own HIV status and telling the child the HIV status of a parent.

Research objectives and design

The study addressed the following research questions:

1. What are the characteristics of families who disclosed the child’s HIV status or the parent’s HIV status to the child?
2. What programmatic choices have NGOs made to facilitate disclosure?
3. Are disclosed children psychosocially healthier than children who were not disclosed to as measured by the Strengths and Difficulties Questionnaire (SDQ)?

Both qualitative and quantitative methods were used to better understand disclosure. Twenty-one in-depth interviews with counselors, social workers and program managers working in each of the four NGOs were conducted between March and July 2011. Quantitative data consisted of extraction of routine program monitoring information (demographic, health, psychosocial, and nutritional data) on children and their families from two of the NGOs selected for the study.

Literature review

The study was guided by an extensive literature review examining the disclosure of HIV status to children. From this review, the following findings are salient:

- Disclosure to children has shown to be associated with positive familial relationships, better psychosocial adjustment and increased adherence to treatment.³⁻⁹ Children who know their HIV status have been shown to have higher self-esteem and better relationships with their caregivers than those who are unaware of their status.^{10,11} Likewise, the disclosure of a mother’s HIV status to her child has also been associated with improved health outcomes for both mother and child.^{10,12,13}

- Most reports strongly suggest disclosure should be addressed within a family context, led and initiated by caregivers instead of healthcare providers.^{11,14–16} Disclosure also serves to strengthen the parent-child relationship, facilitate communication and promote a child's and mother's coping.^{17,18}
- There are common challenges caregivers face that act as barriers to disclosure; including stigma, being emotionally unprepared, and a lack of knowledge and skills to communicate disclosure.^{3,15,19–22} Many parents fail to disclose to their children due to guilt and fear.^{10,14,18,20,23–25}

As of 2011, only two journal articles and one report had been published on disclosure to children in India; both articles examined disclosure to children in North India and a report commissioned by AIDS Alliance looked at facilitating HIV testing and disclosure in Andhra Pradesh.^{3,22,26} Published work on disclosure in Tamil Nadu and Karnataka was not available which is noteworthy given that both states have high HIV prevalence rates.

Findings

Factors Influencing Disclosure

Data showed the following factors influenced disclosure:

- ART initiation
- Child asking questions
- Parental consent and support
- Poor-health of family members or child
- Age and maturity of child
- Education of parents
- NGO role and approaches to disclosure

Disclosure was rarely an active decision made by a parent. Instead, disclosure occurred as the physical, social, psychological and economic consequences of experiencing HIV/AIDS became increasingly significant in the family and parents found withholding information from a child to be increasingly difficult. Children often gained partial information about their HIV status through visits to the ART center and frequent sickness. NGOs were the strongest advocates for disclosure and there was little evidence of a commitment to supporting disclosure in ICTC and ART centers. The event of an HIV test was not a predictor of disclosure to children, indicating that the patterns of disclosure for children do not fit into the model of pre-test and post-test counseling used for adults.

ART initiation was the strongest predictor of disclosure. Both the qualitative and quantitative data highlighted the role of age and maturity in influencing disclosure. There was also a strong suggestion in the data that parents should be the lead actors in disclosure, though this must be guided by the child's maturity, and supported by a health care worker whenever possible. This is also echoed in the NACO guidelines for HIV Care and Treatment in Infants and Children.²⁷

Programmatic choices by the NGOs accounted for the following statistically significant differences in children who knew their status:

- NE Delhi NGO: Disclosure more likely with median age 11 year old male child, who is on ART and has an HIV positive parent on ART.
- Chennai NGO: Disclosure more likely with median age 14 years old female child currently on ART who is a double orphan.

NGO Programs to Facilitate Disclosure

NGO staff felt knowledge about their own HIV status and treatment was the right of a child and highlighted the following steps to be crucial in facilitating disclosure:

- **Initial assessment and enrolment:** Although many families and children had accessed HIV testing and/or ART services prior to enrolment in the NGOs program, it was rare for a child to know their HIV status at enrolment.
- **Building rapport:** NGO staff developed a relationship with children and families, built trust and was therefore able to discuss the issue of disclosure.
- **Assess whether a child is ready to learn about their HIV status:** A child's understanding was assessed informally, usually through the questions a child was asking. If NGO staff found the child was curious about his or her status, or parents to be frequently sick, or the child to be on ART, disclosure was encouraged.
- **Work with parents:** NGO staff played an important role in initiating a discussion on disclosure with parents (where relevant) and in supporting parents and caregivers to disclose. Parents were shown disclosure could be a powerful step in equipping a child to deal with the future. In some cases NGO staff were present when a parent disclosed to a child and one NGO disclosed directly to children without the presence of a parent, but after seeking parental consent.
- **Disclosure:** In all four NGOs, children are given age and maturity-specific information. HIV was often described as a 'worm' or 'germ' in the blood and stories and images, stories and puppets were used to explain HIV and the importance of ART and good nutrition.
- **Follow-up:** Follow-up after disclosure was seen to be essential to develop a child's understanding of HIV and especially to provide support to adolescents.

Psychosocial Health of Disclosed Children

Finally, the study found that SDQ total difficulties score did not differ between disclosed and non-disclosed children. We interpret this to mean disclosure fosters psychosocial well-being with parents and others as there is additional information and more openness in family relationships without any apparent (measureable) additional psychosocial problems.

Future directions of disclosure programming

The public health significance of disclosure increases as more HIV positive children are living into adulthood. Our findings suggest that while NGOs play a crucial role in facilitating disclosure, ART centers need to provide appropriate counseling to mothers and children on disclosure, particularly because ART initiation is a turning point for disclosure. The following areas should be considered to strengthen and develop disclosure programming:

1. Build and/or strengthen state institutional capacity, particularly the ART centers, to improve the provision of care and support to mothers/caregivers and children in the disclosure process;
2. Build and/or strengthen NGO capacity to support or undertake disclosure activities;
3. Expand and update national guidelines, informed by the global experience, on pediatric disclosure and a toolkit on disclosure to children;
4. Based upon the national guidelines, develop training modules and resources on disclosure;
5. Develop a robust monitoring and evaluation process in NGOs to capture child health outcomes and the disclosure process over time.

BACKGROUND

Telling a child they are HIV positive, or that their parent is HIV positive, is a challenging and sensitive issue for parents, health care workers and HIV counseling and testing centers. While global research has shown positive health and psychosocial outcomes for children and parents post disclosure, many children continue to reach adolescence without knowledge of their HIV status. There is little guidance and support available to health care workers and parents about how, when, and why to tell children their HIV status and answer their questions about taking tablets, visits to hospital, intermittent sickness and their future.

This study responds to the scarcity of knowledge and evidence on disclosure to children in India. The study was conducted with four NGOs serving orphans and vulnerable children (OVC) in Bangalore, Chennai, Delhi and Mumbai, cities in states with a high prevalence of HIV. All four NGOs have developed resources, models and expertise to facilitate disclosure. The study forms part of an evaluation requested by the United States Agency for International Development in Delhi, India (USAID/India). The evaluation was conducted as part of the Orphans and Vulnerable Children Comprehensive Action Research Project (OVC-CARE) currently being implemented by the Center for Global Health and Development at Boston University.

Table 1: India HIV Data

	India
HIV prevalence	0.36% ¹
People living with HIV	2.4 million ¹
Children living with HIV	100,000 ²⁸
Children Registered for ART	79,719 ²⁹
Children alive and on ART	22,837 ²⁹

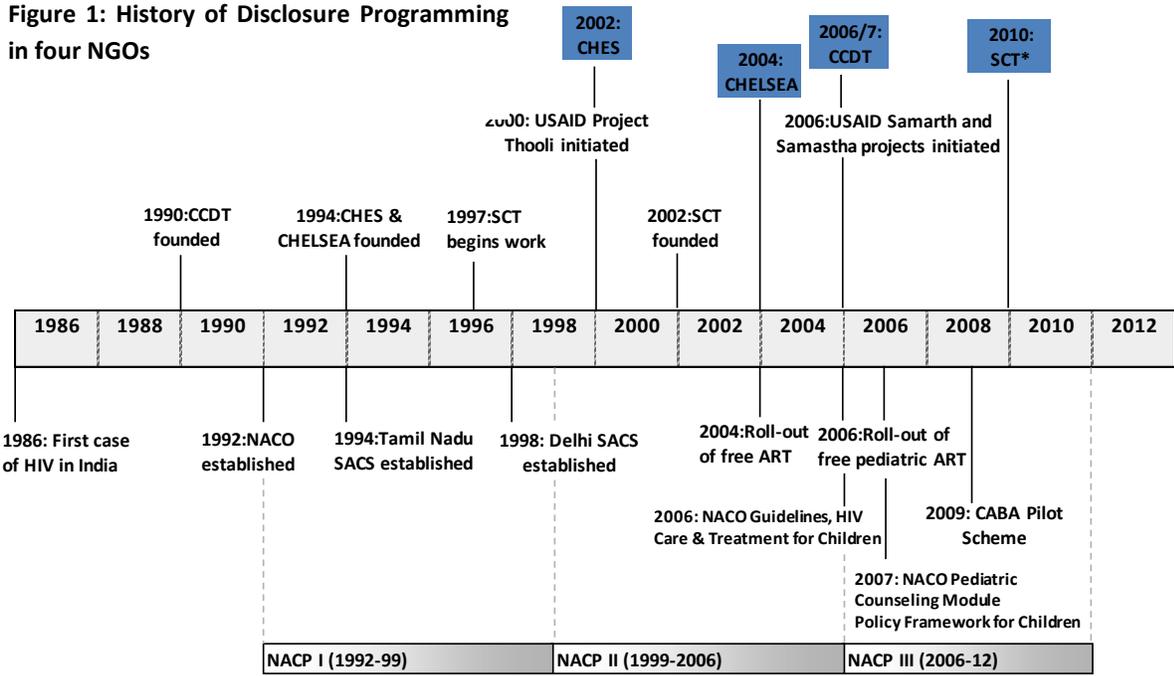
India currently has the third largest number of people living with HIV in the world¹, including an estimated 100,000 HIV positive children, many of whom are orphans.² This may be an underestimate as NACO recently estimated approximately 57,000 children are being infected per year. The primary mode of transmission is mother to child transmission (MTCT).³⁰

Over the last six years, there has been an increase in services, programs and policies for children living with, and affected by, HIV in India. Civil society has continued to play a crucial role in providing services to vulnerable populations, strengthening linkages to the National AIDS Control Program (NACP) and the State AIDS Control Societies (SACS), and providing both community-based and residential care to OVC. As seen in Figure 1, all four NGOs included in the study began their work during India's first National AIDS Control Program and were founded before free ART was available in India allowing them to develop significant expertise in HIV care, support and treatment.

Free pediatric ART was introduced in India in 2006 (two years after the introduction of free ART). Improved access to treatment increasingly allows children living with HIV to reach adolescence and adulthood, which represented a turning point for programming for children living with, and affected by, HIV. And, programs for children therefore had to evolve and respond to this change. In the same year, the National AIDS Control Organization (NACO) released a set of guidelines on HIV Care and Treatment in Infants and Children that included a section on pediatric disclosure²⁷ and over time, the NGOs, which were selected for the study, began to implement disclosure interventions as well as other psychosocial and health services which addressed the long term needs of a child.

The National AIDS Control Program 2007–2012 (NACP III) recognized the need to scale up care and treatment services for children and published a “Policy Framework for Children and AIDS” in 2007, which included a goal to ensure that affected children and families are not excluded from the same services and opportunities as others in their communities. A pilot of the Children Affected by AIDS (CABA) Scheme was initiated in ten districts in 2009 to strengthen linkages between services and improve referrals for children.

Figure 1: History of Disclosure Programming in four NGOs



Disclosure programming *SCT had organizational expertise in disclosure from a residential program which was initiated in 2001.

Today, with an increasing population of HIV positive children surviving into adulthood, a continued focus on ensuring child have access to necessary services and programs is essential. The development of a knowledge-base on how best to serve OVC is a crucial component of responding to the emerging developmental needs of children and adolescents. There is a dearth of research and programmatic knowledge on disclosure of HIV status to children in India, a lack of awareness of available guidelines,

which are not tailored to the diversity of settings in which disclosure occurs, and a lack of access to training on disclosure.

This report presents both qualitative and quantitative findings of the study and suggests future directions for disclosure programming. The research design and objectives are presented in Section 2 followed by a literature review (Section 3) to situate the study in the context of global research on disclosure. Section 4 reports the main findings of the research and Section 5 offers concluding remarks and recommendations for future disclosure programming.

RESEARCH OBJECTIVES AND DESIGN

A mixed methods study was designed to better understand disclosure in children and families receiving services from in four NGOs in four different states, and in the context of community-based and residential care. Table 2 presents the study aims and corresponding research questions.

Table 2: Study Aims and Research Questions

Study Aim	Research Question
1 Understand factors which influence disclosure and the challenges of disclosing to children in India.	What are the characteristics of families who disclosed the child's HIV status or the parent's HIV status to the child?
2 Document approaches used by four NGOs in India to facilitate disclosure.	What programmatic choices have NGOs made to facilitate disclosure?
3 Describe psychosocial well-being among disclosed children in NGO programs.	Are disclosed children psychosocially healthier than children who were not disclosed to as measured by the Strengths and Difficulties Questionnaire (SDQ)?

The study was guided by a literature review on existing research on disclosure. Table 3 shows the study sites and the differences in programs offered by each NGO.

Table 3: Study Sites

NGO	Location	Programs	No of interviews (Primary language)
Women's Action Group...Children Health Education Ladies Senior Citizens Environment Awareness (CHELSEA)	North-East Delhi	• Community home-based care	5 (Hindi)
Community Health Education Society (CHES)	Chennai	• Community home-based care • Residential care	5 (Tamil)
Committed Communities Development Trust (CCDT)	Mumbai	• Community home-based care • Residential care	6 (English)
Sneha Charitable Trust (SCT)	Bangalore	• Residential care	5 (English)

Qualitative Methodology

Guided by the literature review, an interview schedule was developed and pre-tested. The interview guide (Appendix 1) asked respondents to use their experience in disclosure programming to discuss the following:

- How children first receive information about HIV
- The role parents and siblings played in disclosure
- The role the NGO plays in disclosure to a child, including guidelines and policies on disclosure

- Factors affecting disclosure (age, gender, orphan status, psychosocial well-being, sickness, ART)
- Reactions post-disclosure
- How the NGO deals with the death of a parent or a child who is distressed
- Training received on disclosure
- Recommendations and best practices

Interviewees were asked, wherever possible, to refer to cases and scenarios they had observed in the field or addressed in the course of their work with children and families.

Table 4: Description of Respondents (n=21)

	n (%)
Care context	
Residential care	10 (47.6)
Community Home-Based Care	11 (52.3)
Gender	
Female	14 (66.7)
Male	7 (33.3)
Experience in disclosure*	
Delivering disclosure interventions	9 (42.9)
Management	12 (57.1)
Years in organization	
Less than 2 years	2 (9.5)
2-5 years	6 (28.6)
5-10	6 (28.6)
More than 10 years	7 (33.3)
Years in current role	
Less than 2 years	5 (23.8)
2-5 years	9 (42.9)
5-10 years	6 (28.6)
More than 10 years	1 (4.8)

*NGO staff currently working face-to-face with parents and children to deliver disclosure interventions. This includes counselors and social workers working on disclosure. Often management staff also had previous experience in disclosure.

A total of 21 in-depth interviews were conducted between March and July 2011. Social workers, counselors and program managers were interviewed in each NGO. Most respondents had worked in the organization and in their current role for over two years (Table 4) and over 33% of respondents had worked in the NGO over ten years. In CHES, CHELSEA and SCT every staff member directly involved in implementing disclosure interventions was interviewed.

Research assistants conducted interviews in Hindi, Tamil and English with a co-interviewer to aid in translation when required. Interviews were recorded wherever possible, translated and transcribed by a local research company. Data was analyzed in Boston and NVivo 9™ was used to code data and conduct a thematic analysis. In addition, we examined training modules, visual resources

and other tools used by NGO staff to facilitate disclosure.

Quantitative methodology

Quantitative data for this study consisted of routine program monitoring data (demographic, health, psychosocial, and nutritional data) on children and their families from two NGOs, CHELSEA and CHES. The quantitative scores of the SDQ, a standardized psychometric tool, were used as the primary descriptor of psychosocial health of children. Data was entered into Excel™ by the NGO and analyzed in Boston using SAS v9.1 (Cary, NC). Univariate analysis including frequencies, proportions, means and standard deviations were reported. Bivariate and multivariate logistic regression models were used to understand predictors of disclosure.

Due to differences in data reporting and collection between the organizations, it was not possible to compare the two organizations. Thus, the experiences of each organization are separately reported.

Ethical Considerations

Ethical approval was obtained from the Boston University Medical Center Institutional Review Board (BUMC/IRB). All data on children and their families was de-identified and respondents were asked to refer to cases in their interviews without reference to the name of the beneficiary or any other identifying characteristics.

DISCLOSURE LITERATURE REVIEW

The study was framed and guided by an extensive global literature review based on studies examining the disclosure of HIV status to children. Existing research has come from studies conducted primarily in the U.S.^{8,10,19,31–33} Despite higher prevalence rates, there has been little research in low-resource settings on how children are disclosed to and the outcomes of disclosure.³¹ As access to antiretroviral therapies has expanded, children across the world are surviving through childhood and into adolescence.³⁴ For many caregivers and parents, access to treatment is the turning point in beginning to think about disclosure. While there is a growing amount of research from Sub-Saharan Africa, research on disclosure in India remains sparse. This section examines key themes in the global literature on disclosure and existing research in India.

Global Evidence of Disclosure

Positive Health Outcomes of Disclosure

Disclosure to children has shown to be associated with positive familial relationships, better psychosocial adjustment and increased adherence to treatment.^{3–9} Children who know their HIV status have been shown to have higher self-esteem and better relationships with their caregivers than those who are unaware of their status.^{10,11} Likewise, the disclosure of a mother’s HIV status to her child has also been associated with improved health outcomes for both mother and child.^{10,12,13}

As HIV positive children reach adolescence, the public health significance of disclosure increases as: young people begin to take a more active role in decisions about their own health; often become caregivers for their ill parents or siblings, with little support from social services²; become sexually active and risk spreading the disease to their partners.^{14,35,36}

Role of Mothers/caregivers in Disclosure

Most studies strongly suggest disclosure should be addressed within a family context, led and initiated by caregivers instead of healthcare providers,^{11,14–16} and serve to strengthen the parent-child relationship, facilitate communication and promote a child’s and mother’s coping.^{17,18} However, the challenges of disclosure should not be underestimated. Stigma, being emotionally unprepared, and a lack of knowledge and skills to communicate disclosure^{3,15,19–22} all play a significant role in influencing a parent, or caregiver’s, decision to disclose to their child.²¹ Parents have often refrained from disclosing their own status and worry about a younger child’s ability to be discrete.⁵ Many parents do not want to subject their child to potential discrimination or additional burdens, feeling that their children are ‘innocent and vulnerable’. Unlike other chronic or terminal illnesses, HIV bears the additional burden of being sexually transmissible and HIV positive children must deal with the fact that they will have to live with a disease which may alter their family structure and affect their future relationships. Many

caregivers worry that the negative implications of disclosing a child’s status will outweigh the positive ones.²¹ Table 5 outlines the common challenges identified in the literature that caregivers face, which act as barriers to disclosure.

Table 5: Challenges Faced by Caregivers

Literature Review: Challenges Caregivers Face in Disclosure
<ul style="list-style-type: none"> • Feelings of guilt and fear^{10,14,18,20,23–25} • Fear of stigma^{5,21} • Concern about the age and maturity level of the child^{15,37} • Concern over loss of confidentiality²² • Feeling of inadequate support and/or knowledge to disclose^{9,14,15,34,38,39} • A lack of assistance with disclosure from health care providers^{39,40}

Small cross-sectional studies performed in Ghana, South Africa, and Uganda investigated caregiver attitudes towards disclosure.^{9,34,38} In Ghana, 71 caregiver-child dyads were interviewed on disclosure status. While 21% of caregivers interviewed said that they had disclosed to their children, only 49% of those children had knowledge of their positive status, indicating that caregivers were not aware of appropriate methods of disclosure.³⁴ In Uganda, of 42 caregivers and their HIV positive children, 29% of caregivers had disclosed completely; 38% had disclosed partially; and 33% had not disclosed at all.⁹ In Soweto, South Africa, it was found that among 17 caregivers a very small number had told their children about their HIV status.³⁸ All three studies indicated that caregivers wanted more support from healthcare providers in the disclosure process.

A 2006 study performed in Thailand interviewed 103 caregivers of children who were receiving ART. One-third of caregivers reported having disclosed at an average age of 9.2 years. Of those caregivers that had not disclosed, 85% had given inaccurate information to the children they cared for instead of disclosing to them. While a larger majority of 88% of caregivers agreed that disclosure was important, most felt that they would need assistance from healthcare workers. Similar to the studies performed in Sub-Saharan Africa, this study also pointed to the need for better guidelines on disclosure for both healthcare workers and caregivers.⁴⁰

In order to address barrier to disclosure and the challenges caregivers face, existing studies highlight the need for caregivers to have access to support services or health care providers who can aid caregivers to better understand how, and when, to disclose to a child. This support needs to continue over the developmental life-span of the child and family and through the pre- and post-disclosure time periods. This is particularly important as most studies agreed that disclosure is not an isolated event but an ongoing process.^{11,35,41}

Role of Health Care Workers in Disclosure

In most cases, health care workers see their role primarily as working with mothers and caregivers to facilitate disclosure. While healthcare providers tend to agree that disclosure is an important issue for

both children and mothers/caregivers, many feel ill equipped to offer support and express the need for additional training and guidelines suited to resource limited settings.^{39,42} Published guidelines on disclosure^{11,27,43,44} are believed to be of benefit; however, they have limitations and further work is needed to ensure guidelines are relevant to the local context, and to improve the use of these guidelines by health care workers.^{5,15,37,45}

The decision to disclose to a child is far from straightforward. The variable timing of disclosure can often put health care workers in a difficult situation as they may feel a child should be disclosed to before the caregiver is ready to disclose¹⁴ and health care workers are often caught between feeling ethically obligated to disclose a child's status, and needing to respect the wishes of a parent who may not be ready to disclose.⁴⁶

Research on Disclosure in India

As of 2011, only two journal articles and one report had been published on disclosure to children in India; both articles examined disclosure to children in North India and the report, commissioned by AIDS Alliance, studied HIV testing and disclosure in Andhra Pradesh.^{3,22,26} We failed to identify any published work on disclosure in Tamil Nadu and Karnataka, states which have higher HIV prevalence rates and many children infected and affected by HIV.

In a 2009 study published in the Indian Journal of Pediatrics (Arun 2009), 50 caregivers in New Delhi were interviewed regarding their perceptions about disclosure to children.¹⁵ According to their caregivers, of the 50 children in the study, only 7 (14%) were aware of their HIV status. A majority of the children were given no information about the disease and most caregivers felt that disclosure should not take place before adolescence and that parents should reveal HIV status to children.¹⁵ A number of common barriers to disclosure were identified which included stigma, being emotionally unprepared, and a lack of knowledge and skills to communicate disclosure on the part of the caregiver.

A second study (Bhattacharya 2011) used a cross sectional method to determine patterns of disclosure among 145 North Indian children over the age of five.³⁷ Forty-one percent of children in the study were aware of their status and most had been told between eight and ten years of age.³⁷ Barriers to disclosure were similar to those found in the 2009 study, however many caregivers expressed concern over the child's maturity level. Full disclosure was seen more frequently in caregivers with a higher educational status.³⁷

Both studies focused on patterns of disclosure and potential reasons why or why not caregivers choose to disclose. Neither study assessed the impact of disclosure on the child's quality of life, well-being or psychosocial health.^{15,37} Both studies highlighted a need for support services to work with caregivers through the disclosure process and that caregivers expressed a desire to have more support to be better able to disclose to their children.^{15,37} In particular, as Bhattacharya noted, a focus was needed on communicating to caregivers that disclosure was an ongoing process instead of an isolated event.³⁷ The main conclusion from both studies was a need for more culturally specific guidelines around pediatric

disclosure. However, neither author provided any guidance on the form or content of such guidelines.

Disclosure Guidelines

In 1999, the American Academy of Pediatrics (AAP) first published guidelines on disclosure. One of the most important messages in these guidelines was that disclosure was not a one-time event, but an ongoing process that should involve parents or caregivers, children, and health care providers.¹¹ A team-based approach, involving physicians, psychiatrists, nutritionists, and other practitioners was advised in order to account for the complexity of the disclosure process. The guidelines noted the added challenge of HIV disclosure (in comparison to the disclosure of other illnesses) and recognized that disclosing a child's status often meant disclosing the status of a parent as well.¹¹ The AAP guidelines were developed in the context of the human and financial resources available in the US health system. However, this document became the foundation for most low-income countries and NGOs and was adapted to a diversity of settings.

In 2006, NACO published Guidelines for HIV Care and Treatment in Children and Infants. A short section on disclosure was included in this manual, and advised that caregivers should take a child's maturity, ability to cope and family dynamics into consideration before disclosing. The manual provides limited, age-specific guidelines for children up to age nine, and advises that disclosure should be an ongoing process with counseling and support available to children throughout²⁷. In addition, guidance on disclosure can also be found in the Antiretroviral Therapy Guidelines for HIV-Infected Adults and Adolescents Including Post-exposure Prophylaxis (NACO 2007)⁴⁷ and the Pediatric ART Counseling Training Modules (NACO 2007).^{48,49}

In 2007 Family Health International (FHI) published guidelines for HIV testing and disclosure⁴⁴ and in 2009, Catholic Relief Services (CRS), with funding from the President's Emergency Plan for AIDS Relief (PEPFAR), produced a training curriculum for Psychosocial Care and Counseling for HIV-Infected Children and Adolescents. The CRS guidelines outline approaches to pediatric and adolescent disclosure, within the context of resource-limited settings.⁵⁰ Much like the AAP guidelines, the CRS guidelines advocate for a team-based approach to discussing disclosure with caregivers and supporting them through the process.^{5,50} These teams include doctors, nurses, nutritionists, physiotherapists, occupational therapists, social workers and other health professionals, in addition to the child's caregivers and family.⁵⁰ In an ideal situation, every child with HIV would have access to a team of support; however, in reality it is often a single healthcare provider and caregiver who must disclose to a child resulting in a significant amount of pressure on the individual healthcare provider to play multiple roles to support disclosure.

Most recently, WHO issued their guidelines on HIV disclosure counseling to children under 12. There are reported health benefits to children of knowing both their own and their parent's status. They make two Strong Recommendations and two Conditional Recommendations encouraging disclosure and the disclosure process while admitting that the evidence was either weak or absent for their proposed recommendations.⁵¹

FINDINGS

First Source of Information about HIV

According to NGO staff, children receive their first source of information on HIV/AIDS from: the media (radio, posters and television); in school; and, through community awareness programs run by NGOs. In most states, some information about HIV/AIDS was included in the school curriculum. Children rarely receive their first source of information on HIV/AIDS directly from a parent or a family member who later may be involved in disclosure to child. Only one respondent mentioned family members when asked where children receive their first source of information on HIV: ‘the child may learn...from his mother’. Other respondents discussed how children first learn about HIV by overhearing family members talking, observing their parents falling sick and experiencing the death of their parents. NGOs running residential programs highlighted how often a child’s first source of information about HIV is synonymous with experiencing HIV-related stigma.

“Many a times the children who come would have heard of it because they would be already stigmatized by their relatives or people when they were in the family saying ‘you are a HIV child’. It is in their mind that they have AIDS. They know it but in a very negative way.” (CCDT)

“We had a five year old boy, his parents died and he was with his uncle...they kept him for a few months outside their house and food were given in aluminium plate. When this boy came here, he was so attached to us. Three months later, his uncle visited and brought him a packet of biscuits, the child threw the biscuits away...we asked him why he did it and he said he was discriminated against so badly and asked why his uncle was coming to see him here [in the residential care home] when he never wanted him when he was there [at home].” (CHES)

Friends and peers also play an important role in introducing children to HIV/AIDS. In one case, where the children were in a residential care home:

“Other children in the school talk about the center as a place only for HIV positive children and all the teachers know that these students are from the center. Parents know it is an HIV center and tell their children who then talk about it in school. Children would come and ask me ‘why do other children say HIV is a disease?’ ” (SCT)

However, information from peers, friends and the media was not considered to be complete or detailed and several respondents highlighted that children are left with misconceptions about HIV.

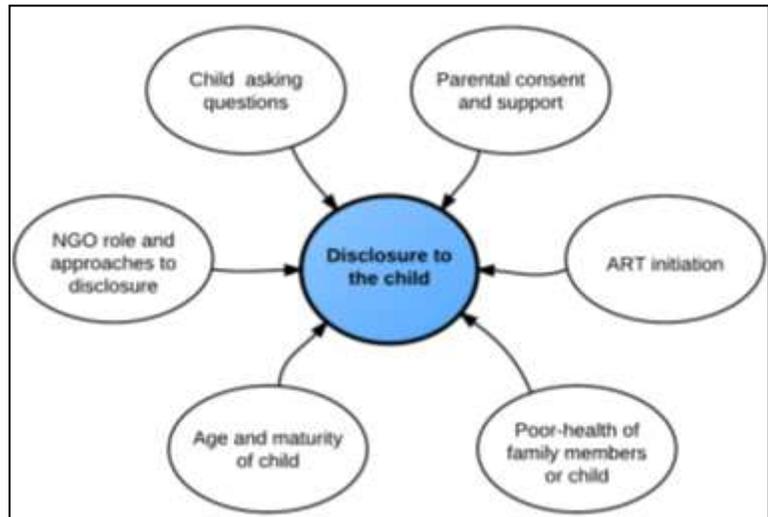
Notably, direct disclosure to a child by an adult was very rarely the first time a child had heard about HIV. Children receive information about HIV from external sources and usually, by the time disclosure begins, have some understanding of HIV. Or, children are aware that their life is different from the lives of other families and children and, in some cases, even their own siblings or extended family.

Factors Influencing Disclosure

Respondents were asked to discuss how a child's age, gender and orphan status affected disclosure. Figure 2 presents the results of a thematic analysis of factors which influence disclosure. Although these factors are interconnected, this section uses qualitative and quantitative data to discuss each of the individual factors. The role of NGO and programmatic choices made by each organization were considered crucial to initiating and facilitating disclosure and these will be further examined in Section 4.6.

Child Asking Questions

Figure 2: Factors Influencing Disclosure



Staff in all four NGOs agreed on the importance of using a child's questions to assess readiness for disclosure and there was a strong emphasis on the importance of advising parents to disclose when the child begins to ask questions.

"Because the child is eating medicines he has questions in the mind...why it is so, why is he so ill, and we tell his parents to tell him his status."(CHELSEA)

"It is always better to disclose when the child is asking such questions. When the child is curious to know the reason, it is always better to tell them" (CHES)

"Children want to know why they fall sick frequently and why others don't fall sick in school. They are asked questions by classmates and they find it difficult to answer...they ask the parents what is wrong with them. At this stage they have to be told that there is some problem with the blood and they need to take medicine for life, better to avoid the term HIV in the initial stage. (CHELSEA)

Qualitative data showed a child's questions played a crucial role in initiating disclosure. Age was also an important factor given that as children grew older the nature of their questions changed and their dependence on their parents to answer questions decreased as they were able to read signs in Integrated Counseling and Testing Centers (ICTC) and ART centers, and seek information from other sources.

"At certain age, the parents would feel that child is eager to know... he would quarrel with parents... he would ask them to explain why they are eating medicines ...or why he is taking medicines. So, they would feel that it is time to inform the child ... because he is eager. Out of eagerness, he may seek information outside...and incomplete information is dangerous." (CHELSEA)

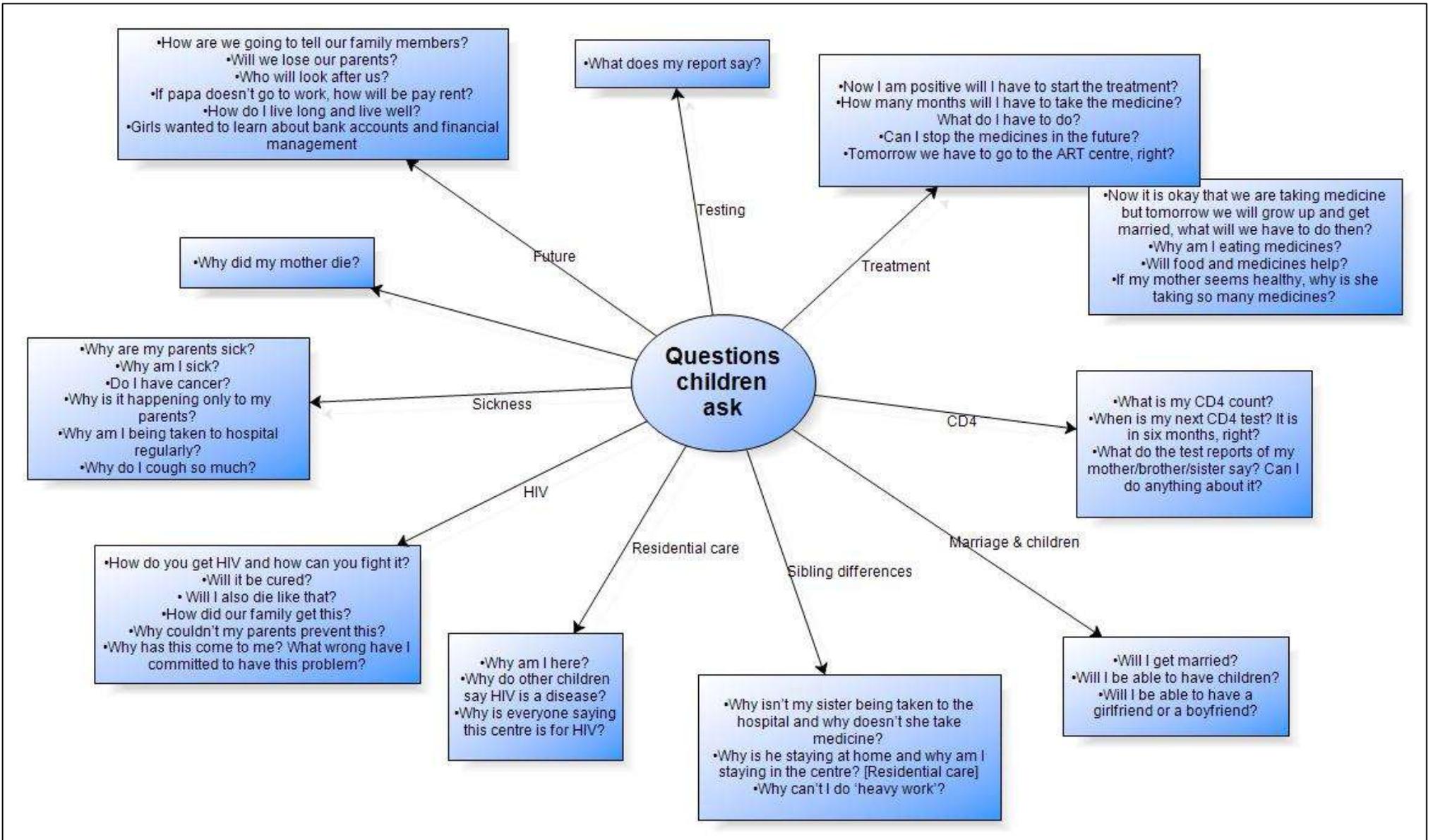
“They start reading in the hospital. There are posters written in Tamil clearly. They read them, go to parents and ask them about it. When we go to visit them, they ask us and get to know. Many classes are conducted; they attend and get to know these things. They also ask why they only are taken to NGO. By these interactions, to some extent they are clear in their minds. By 12 years, disclosure is almost complete. They understand everything completely.” (CHES)

Many NGO staff members discussed the importance of answering questions without lying to the child. In the context of community based care, answering a child’s questions had to be balanced with the need to respect parent consent for disclosure and NGO staff described their dual role in advising a parent to answer the questions a child was asking, and in answering a child’s questions without talking about HIV. In the CHES residential care home, if disclosure occurred it was almost entirely based on a child asking questions. SCT staff highlighted their policy of ensuring children were always given truthful answers to their questions and the CCDT residential care home was more proactive about disclosure and tried to ensure disclosure of the child’s status was linked to a child’s HIV test and maturity and less to the growing curiosity of a child.

NGO staff also discussed the nature of questions children asked (Figure 3). Children most often asked questions about ART, sickness and their future (marriage and sexual maturity). While the questions can be aggregated into the broad categories presented in Figure 3, it is important to note many of the questions are about the child’s family members – children ask why family members are sick and what will happen to them in the future. Age was an important determinant of the content of the conversation. That is, as children got older they were said to have more questions, and often have questions post-disclosure. Several respondents also highlighted questions where children asked about themselves *vis-a-vis* other children. Comparing themselves to other children or siblings appears to be part of a process through which a child understands how being HIV positive does, or does not, make them different. Disclosure brings about new kinds of relationships for children and the questions expressed in Figure 3 are a way to understand and navigate the meaning of living with, or being affected by, HIV and how this changes with maturity and other life events. No examples were given of questions a child had before an HIV test. This is consistent with other findings which show the disclosure is not linked to HIV testing as pre-test counseling is rare and infrequent for children.

While a child’s questions often trigger disclosure and inform the nature and pace of disclosure counseling, a child’s questions and responses also guide post-disclosure follow-up. Indeed, responding to a child’s questions, seeking information from a child about how much they know about HIV, how this knowledge evolves and what their concerns are forms a crucial assessment component of child-centered counseling, an approach used by all four NGOs. This ethos also underpins the importance of listening to a child to uncover their current level of understanding and providing maturity specific information based on this to enhance positive well-being.

Figure 3: Questions Children Ask



Age and Maturity of Child

As expected, both the qualitative and quantitative data suggests older children and children involved with the NGOs for a longer time are more likely to know their status. This is both related to the sexual maturity of the child (onset of puberty is reported to be a triggering factor for disclosure) and the growth and increasing maturity in cognition (older children being reportedly more able to understand HIV and their HIV status). The age group of 11-15 years was generally the range that respondents felt to be appropriate for disclosure. Respondents in CHELSEA had experience of disclosing to children at the age of five or six years while CHES staff cited fewer cases where children had been disclosed to before the age of ten. SCT initiated a disclosure intervention for the children between nine and thirteen living in the residential care home. The following comments highlight the different perspectives on how the child's age and maturity triggers disclosure:

"Older children or adolescent children need to know their status because they are very inquisitive and they may experiment. So to know what care they need to take... it is extremely important for them to know for their own well-being and the well-being of their partner if they get into physical relationship. (CCDT)

"Now children in the 7th class also quite mature. They see TV advertisements and are curious to know but parents change the topic or change the channel to avoid discussion. (CHELSEA)

"Above 8, 9 years, the child would have knowledge... above 10 years; the child would definitely have such knowledge. Such children would take care of their parents... we have seen that such children ensure medicines adherence of their parents...if the child is above 15 years... we tell them that they have HIV in the way we tell adults." (CHELSEA)

"12 plus would be the excellent age group to disclose and children beyond 12 years in the Indian context they would cope easily with the situation...girls are very mature in taking, accepting and receiving the information and taking care of their parents" (CHES)

"13 or 14 is definitely the time [to] spend time doing the complete disclosure...there could be sexual activity before that, but that is not presumably common in our culture... also they are physically mature, many times children are delayed in their maturity even physically, so I usually wait till 13 or 14 years unless there is some specific reason I want to do it earlier." (SCT, discussing practice at the local hospital)

NACO guidelines cover paediatric disclosure and recommend providing maturity-specific information to children between the age of two and nine years²⁷.

Maturity and Gender

Most respondents believed a child's gender influenced when a child was disclosed to although a small minority of respondents felt gender did not affect the disclosure process in any way. Every respondent who discussed gender felt girls could be disclosed to earlier than boys because girls were considered to be more ready to learn about their diagnosis. Onset of menstruation, the role girls played as caregivers to parents and siblings in the household, and a perception that girls were more mature were the primary reasons (Table 6). Respondents also noted that girls and boys asked different questions and voiced different concerns post disclosure (see Section 4.7).

Table 6: Gender Differences in Age of Disclosure

Reasons Given for Disclosing to Girls Earlier than Boys
<p><u>Menstruation</u></p> <ul style="list-style-type: none">• <i>“I have seen that girls have a better maturity level, she will be more understanding compared to the boys. If she has reached puberty...we can explain to her about everything. Whereas the boys will find it difficult to understand these things.” (CHELSEA)</i>• <i>“Girls [are disclosed to sooner], as they get periods and all, they have to maintain hygiene and cleanliness. Their mother herself tells them about it. We will have to tell a girl child soon as she will be matured by 12 years and she has to maintain hygiene.” (CHES)</i>• <i>“Girl children would be communicated to [about their status] as earlier as possible as they would attain age.” (CHES)</i>
<p><u>Caregiving role in the household</u></p> <ul style="list-style-type: none">• <i>“Girls become more responsible and start taking care of younger children. Boys do not understand this late. [Disclosure] Can be done at 10 – 11 years. They come to know better about the family as they stay at home for a longer time as compared to boys.” (CHELSEA)</i>• <i>“Most girls are more caring for parents so they are told.” (CHELSEA)</i>• <i>“Girls mature immediately, they become responsible, they take care of parents and they are very concerned about their parents” (CHES)</i>• <i>“If the parents are sick and there is one girl and one boy, the girl has to leave the school and take care of parents and cook for the elder brother. I think these kinds of early responsibilities will give them maturity to understand the gravity of the situation and they become adults very earlier. Adults not by their age but by understanding the situation.” (CCDT)</i>
<p><u>Maturity</u></p> <ul style="list-style-type: none">• <i>“Girls are smart compared to the boys...girls become more careful after knowing the status of her or her family boys don't become careful.” (CHELSEA)</i>• <i>“Girls are more sensible. They will listen to you more attentively or they know.” (CHELSEA)</i>

However, quantitative findings showed that girls receiving care from CHES and boys receiving care from CHELSEA were more likely to be aware of their HIV status. While respondents from CHELSEA believed girls can be told at a younger age, the quantitative data from CHELSEA showed they informed the boys more often. These gender differences are probably driven by the programs' choices which apparently differ from the NGO staff perceptions. It could also reflect the fact that boys learn their HIV status through other external sources.

Partial Disclosure

As children grow older, absorb information, begin to access treatment, overhear conversations and observe family interactions, 'partial disclosure' often occurs even though the child may not have engaged in a direct conversation about HIV. Four respondents clearly defined partial disclosure in their interviews (Table 7) and others referred to partial disclosure or 'partial knowledge' as children having incomplete information about HIV and their own HIV status.

Table 7: Partial Disclosure

Definitions of Partial Disclosure
<p><u>Respondents</u></p> <ul style="list-style-type: none">• <i>“Partial disclosure is when the parents consider the other routes of transmission but not the sexual route of transmission.” (CCDT)</i>• <i>“Partial disclosure would occur on its own...she would start thinking why she has to take medicines, why CD4 has to be conducted ... every 6 months, she has to give blood...so, partial disclosure will be made during this process...” (CHELSEA)</i>• <i>“Children on ART, even 6-7 years old know the problem to some extent; we can say partial disclosure is there among these children.” (CHES)</i>• <i>“Even younger children are aware of some information about their infection and that is partial disclosure... children who are not aware of HIV and AIDS but about their infection and children who are aware about HIV and aids is termed as full disclosure.” (CHES)</i>
<p><u>NACO guidelines on HIV care and treatment in infants and children</u></p> <ul style="list-style-type: none">• <i>“What’s happening to the body and what treatments will help to resolve this, rather than naming the virus or illness. Complete disclosure involves open discussion about the virus, infection, and all other issues relating the HIV infection. This must be done together with the child and parent/caregiver.”²⁷</i>

Partial disclosure was felt to be some knowledge of HIV, but no knowledge of one of the four causes of transmission, or knowledge of illness and tablets, but no knowledge of the vocabulary to describe the illness and tablets. In SCT, children denied knowledge of an ‘illness’ but remembered they had a ‘worm’ in their body and HIV.

“When I ask if they have any illness, they say ‘no’, but then when I said ‘do you remember anything about a worm in your body’ and ‘do you remember that Doctor [who conducted the disclosure session] and what she explained, then they say ‘yes, we know about how all the children have HIV in Sneha Care Home.’” (SCT)

As shown, partial disclosure can be part of a strategy to provide selective information to a child or it can occur over time without any intervention, and is often beyond the control of caregivers, NGO staff or ART counselors. While the NACO guidelines specify that parents should be involved in disclosure, they do not specify who should be involved in partial disclosure. A Pediatric ART Counseling Training module stated that partial disclosure to a child is favorable and the first step to full/complete disclosure.

“Ideally, disclosure to the child is a process that starts with “partial” disclosure and eventually proceeds to full disclosure. By starting with partial disclosure, children become comfortable with the concepts presented. In general, partial disclosure should be recommended as a way for caregivers to begin the disclosure process.” (NACO)

When a child begins medicine and visits the ART center, the process of on-going exposure to the markers and signifiers of HIV are initiated. Partial disclosure can be a strategy employed by caregivers or occur through other means. Given the varying definitions of partial disclosure it is somewhat difficult to

ascertain how much information a child needs in order to be 'partially disclosed.' Encouraging partial disclosure could have negative consequences if it compromises giving children maturity-specific information and is used to avoid discussing HIV.

One respondent in SCT described the knowledge a child had when she arrived at the residential care home:

"When I spoke to a child who just arrived in SCH (8 years old), she explained that her father was sick and he went to a doctor and she and her mother went with them. She was sitting outside and the doctor was explaining to her father and mother that they have an illness, it is not curable and they have to take medicine. But, she did not know it was HIV/AIDS." (SCT)

The concept of partial disclosure highlights a) that disclosure is not a one-time event, but a process where children gain access to information about HIV and their own status over time, through a variety of sources; and b) that telling a child about 'tablets' or sickness in vague terms is not seen to constitute disclosure of HIV status.

Unplanned Disclosure or Children Finding Out

Partial disclosure can often lead to a child finding out their status and their parents' status, without being told by an adult. NGO staff described cases where children were already aware of their status and their parent's status when disclosure occurred, highlighting a child's ability to absorb information from a variety of sources, and that disclosure is not always an interaction between a parent and a child, but influenced by the wider social networks a child is part of.

"There are also children who know their status, but their parents think that their child does not know. Children are very fast to understand– they are on medication, going to hospital, getting sick, so they come to know through all this, but do not ask parents and hence parents think that their child does not know." (CHES)

Most respondents highlighted that parents preferred to tell children once they were older.

"They have their own view of when it is appropriate, they don't think eight or ten years is appropriate most of the time, maybe they are older, they are [in] high school, college maybe, they are not really okay with the discussion with the child." (SCT)

"They are quite reluctant about disclosure, especially even for small children, they don't want them to know. When the child is 15 or 16 year old, then they are ready to share something with the child." (CCDT)

However, there was agreement that parents were generally apprehensive about disclosure and discussion about disclosure was most frequently initiated by NGO staff.

ART Initiation

Watching a parent take ART, visiting the ART Center, reading posters about HIV and starting ART were said to be a key factors that influence disclosure. Previous studies have also shown that access to treatment is often the turning point for a parent to begin to think about disclosure to a child.^{36,52}

Quantitative data show a child is 13.4 times more likely (CHELSEA) and 8.13 times more likely (CHES) to know their HIV status if they are on ART. Furthermore, children are 1.25 (CHELSEA) or 1.30 (CHES) times more likely to be disclosed to about their parents' status if the parent is on ART.

If the child, a parent, or a sibling is on ART, disclosure is more likely because of a child's increasing curiosity, a higher likelihood of partial disclosure and an increasing emphasis from each NGO to prepare the parents to disclose to the child. The NACO Guidelines on HIV Care and Treatment in Infants and Children recommend that readiness for disclosure should be examined during the assessment of treatment preparedness. Although, these guidelines also state that 'disclosure is not a prerequisite to start ART but disclosure is encouraged when caregiver is ready and child is deemed to be mature and can keep secrets'. However, once a child starts ART, disclosure is recommended as a strategy to address non-adherence to ART²⁷.

Respondents highlighted how children on ART who visited the ART center on a monthly basis received information about HIV.

"Any child who has been taking ART knows somehow or the other that they are positive." (CCDT)

"In 2008 and 2009, we started looking at how children would come to know about infection. What we found is that not every child knew about their HIV status but every child who enrolled in the ART center knew about the infection within them but they would not know it as HIV." (CHES)

"Children went to ART Center with children and when they would go there, they would know that children were taking ART medicine...they would read all posters displayed in ART Center." (CHES)

Living with parents or siblings on ART also leads a child to ask questions:

"The children sometimes ask that their mother seems healthy then why does she take so much medicine." (CHELSEA)

"When they take medicines regularly, they have a small doubt that other children are all fine, but we are taking medicine regularly. And they ask their mothers regularly: if sister is ok, then why is she not taken to hospital or given medicine. Mothers to some extent give information and try to pacify them. We tell the mothers that this is the right time to disclose to the child." (CHES)

Most respondents discussed how they placed an increasing emphasis on persuading and preparing parents to disclose if the child had started ART without disclosure, or if the child was asking questions about why parents or family members were taking tablets twice a day.

“There are chances that children shift from pre ART to ART...when the child is asking ‘what is the reason, why do we have to take it?’ it is then that the time mother tells them about HIV.” (CHES)

“If a child is starting ART, counseling is provided on ART and then it is easier to tell the child. If they get OIs it is easier to tell the child because they start ART. ART can help when it comes to talking about disclosure.” (SCT)

“Finally one day she [mother] decided to tell him. She asked him do you know why I eat these medicines every day morning and evening...he said he already know that she was HIV infected.” (CHELSEA)

“Yes, after the medicines are given they become curious. Especially after medicines for 6 months, when the weight increases, the child starts taking interest in the treatment.” (CHELSEA)

In SCT, ART was the most salient signifier of being HIV positive and some children believed that only those children who were on ART were HIV positive.

“Some of them think that if they are not on ART they do not have HIV and those on ART have HIV, those who are getting sick have HIV.” (SCT)

Although ART was the strongest predictor of disclosure, 18.3% of children in CHELSEA and 67% of children in CHES who are on ART have not been disclosed to highlighting the importance of other factors.

Poor health of Family Members or Child

Sickness of Child

Disclosure was seen to be important in answering a child’s questions about why they were sick so frequently and, in some cases, why they were sick more often than other children:

“If other children get fever, they are cured in about two days, for these children, it will get cured slightly later – in about one week. Then, the children will ask their mother, ‘why do I have to suffer frequently? Why do I cough so much?’” (CHES)

“If children are falling sick after coming here, that is not perceived by the children to be in connection with HIV, because even staff here fall ill or even other people fall ill...some of the kids, bigger kids, might tell you that we are getting fever because of HIV.” (SCT)

In SCT, sickness was not considered to influence disclosure as children were sent to the hospital run by the NGO and being sick was ‘normalized’ by NGO staff and caregivers. Similarly, in CCDT sickness was also not associated with disclosure; however, this was because most children in the residential care home had learned their HIV status after their HIV test.

Sickness or Death of Parent

NGO staff described their role in counseling parents who were falling sick frequently to disclose to the child. Disclosure was seen to be a crucial part of preparing the child for the role they would have to play in looking after a parent, losing a parent, and the additional responsibilities they may have to shoulder after the death of a parent:

"He knew about HIV/AIDS and he saw that his mother is falling sick, and then with the help of the counsellor the mother disclosed her status to the child." (CCDT)

"If both the parents are ill, then we tell them to disclose as early as possible. If both are admitted in the hospital, children know the situation there." (CHELSEA)

"When parents are affected child will ask about illness. We can avoid two-three times but frequent illness needs explanation...child wants more and more information about his parent's illness." (CHELSEA)

"Many times it happens that the family is very sick or the mother is very sick and child knows only one thing that his mother is hospitalized. Now he needs to be prepared because he may have to live all alone now, if he has siblings he has to take care of them. That is why we have to prepare the child. They should be prepared to take all the adult responsibilities...that is why it is very important to disclose the parent's status to the child." (CCDT)

"Sometimes disclosure of parent's status happens when parents start falling sick too often and the child doesn't know why a parent is falling sick. When the parent starts falling sick the responsibility comes on the child he/she has to miss school, be at home to take care of the parents. Sometimes they don't have anything to eat and the child does not understand why it is happening only with his/her parents." (CCDT)

"If the child knows the condition, at least the child can boil water for the sick person. If the mother is positive the children can be handy in many ways. If she gets sick for few days, they will remind her about medicine." (CHES)

"We tell the mother to disclose when the father is sick. Because if the child asks after the death of the father about the reason, it will be difficult, it is better to tell before." (CHES)

Disclosing while a parent was sick was seen to be favourable to disclosing a parent's status after a parent had died. However, many respondents felt that waiting until a family member was sick was not ideal for disclosure.

"Later they become sick. At this time if children come to know about their status, it is very bad for children. They think that parents have not told about this till date." (CHES)

In one case stigma associated with death and HIV led to a child asking questions:

"There was one family that they had three male children and father had died...children started asking so many questions when they saw the father was not allowed to be buried...and then mother told them that the father had got infected with disease and father's body could not be consumed due to existence of this disease and like that." (CHES)

Respondents felt caregivers or extended family were more likely to disclose to the child as they did not experience the same feeling of guilt and shame that parents experienced. The NGO also played a prominent role in the child's life if one or both parents had died, which included a more significant role in deciding when disclosure should occur. Quantitative data from CHES showed that double orphans were more 1.5 times more likely to be disclosed to in comparison to single orphans or non-orphans.

However, children in residential care homes, many of whom were orphans, were still said to be unaware of their own and their parents' HIV status at enrolment and unaware of the cause of death of one or both parents. As shown above, sickness in a family does not automatically lead to disclosure, but to an increasing number of questions, a great need for NGO support due to increased family vulnerability, and an emphasis by each NGO on persuading parents to disclose.

Siblings and Peers

In addition to parents and the child, sickness of a sibling or a peer in a residential care home could also influence disclosure. The example below highlights the role sickness can play in differentiating one sibling from another and the corresponding reactions.

"If the brother would become sick, he would wonder why the other child [who was HIV positive] was being taken to hospital and administered drugs and why he has to take medicine on daily basis... some children would feel there would be significance given to his brother and extra care administered to his brother and only partial care given to him even though he would be sick and it would cause fighting between both of them." (CHES)

The comment also highlights the role sickness of a sibling or parent can play in influencing disclosure to children who are affected by HIV. As discussed in Section 4.7, disclosure of status to siblings can lead to better care of HIV-infected family members.

In the residential care context, if children living with, and affected by, HIV are living together, disclosure to HIV affected children also becomes salient. Although this is outside the scope of this report, children who are affected by HIV also ask questions about the different treatment children who are living with HIV receive, despite the NGOs attempts to ensure children are treated the same (in one case children received vitamins while others received ART). However, some were said to notice the differences and the monthly trip to the ART centre is one such example.

"She asked me why some children were going to other hospitals, why I was not treating them here, she added that I was great doctor to her, why was I not treating them here... Then she asked me why one batch alone was going to other hospitals every month... I had to tell her that these children got infected with HIV virus from their mother." (CHES)

As one respondent highlighted, these factors lead a child to 'register that something is wrong or different with me or my family'.

Parental Consent and Support

While all NGO staff felt it was the right of a child to know their HIV status, most felt parents had the right to decide whether the child should, or should not, be told their own HIV status. There was agreement on the importance and necessity of parental consent for HIV testing, pre and post-test counseling and disclosure. In practice, parents are more likely to deny disclosure than to be predisposed to it.

“Children should know their status but it is a practice that parents deny. And without parents' consent we cannot do anything.” (CCDT)

Parents are reluctant to disclose to their children for a variety of interconnected factors presented in Table 8. A reluctance to disclose is based on perceptions of HIV in society, particularly the association of HIV with sexual intercourse which results in the belief that discussing HIV status with children is synonymous with discussing sexual intercourse. Parental concerns and barriers to disclosure can be examined in the context of (1) the perceived impact of disclosure on family dynamics and child-wellbeing and (2) the perceived impact of disclosure on a family's social capital. In both cases, it is feared that disclosure will cause a transformative, and negative, change in the life of the child and family, resulting in an erosion of social capital. At the household or family level, parents fear their image will be tarnished in the eyes of the child and worry about answering questions like ‘how did you get it?’ or ‘why me?’. This was especially true for fathers.

Central to a desire to deny disclosure was a belief that disclosure would negatively affect the child's well-being and education. Respondents also described a hopelessness parents felt regarding disclosure and a belief that there was little point in adding to the problems the family or child was already having. This perception was compounded by a belief that: a) disclosure placed a burden on the child, explaining the desire of a parent to protect the child as long as possible (or until the parent was able to) from coming to terms with difficult information, b) keeping a secret for the family, and c) apprehending education and interpersonal relationships with others with the additional challenge of knowing their HIV status. Parents have additional concerns about disclosing to girls due to hygiene during menstruation and worry about their marriage. The ultimate concern of parents is that disclosure to a child will lead to wider disclosure to the community or classroom resulting in dismissal from school, eviction from the home due to stigma, or a failure to marry a daughter who is HIV positive. All these changes may affect the social capital of a family and reduce their level of functioning in the community.

While barriers to testing and initiating treatment were far fewer than barriers to disclosure, guilt, concerns parents had and a related fear of a child learning their HIV status were common barriers to HIV testing, treatment and disclosure.

Table 8: Factors Preventing Caregivers from Disclosing

Perceptions of HIV	
<p>Perception HIV is about sex</p> <ul style="list-style-type: none"> • “Parents think that child will immediately relate this infection to sex but they do not realize they won’t” • “Every person has a picture in his mind that HIV infection occurs due to sexual act” • “Generally parents do not talk about HIV at the home. They fear that the child will misunderstand them and will think that it is because of unprotected sex.” • “HIV/AIDS is very much associated with sexuality. It is such a hush, hush topic...so, when you talk about HIV it is so loaded with sex and sexuality, the parents don't even tell their girls when they start menarche. So how would you tell child about the modes of transmission and all the other things.” 	<p>Guilt and shame</p> <ul style="list-style-type: none"> • “Some feel ashamed that my child is positive because of me.” • “Parent’s feel guilt and blame and want children to be happy”
Impact of disclosure on family dynamics and child’s well-being	
<p>Fear of child’s reaction</p> <ul style="list-style-type: none"> • “Fear that the children may start believing that my father has done a bad deed because of which he got such disease” • “Father would feel hesitant because he would be known to have lived outside to them and they would stigmatize” • “Some people say ‘my child will blame me for being positive’” • “Father would feel that his importance would deplete and he would lose his respect among the children and they would become disobedient.” • “Fear that the child will hate parents and lose respect.” • “When you have to share to your child that you are positive, that becomes a little more challenging for them to share. And then [they ask] ‘Why me?’” 	<p>Belief that there is no advantage of telling the child</p> <ul style="list-style-type: none"> • “Their thinking would be ‘I am already facing so many problems, why should I do this and create more problems.’” • “They ask why do we have to pass this fear to the child.” • “They believe that we all are suffering from this...so, the child would come to know about it sooner or later himself so it is not a special agenda” • “They are scared to reveal it and say: let the children find out by themselves.” • “They feel that children can't understand ‘Why do we need to tell the child, we are there to take care of the child?’” • “They feel ‘what is there to tell, everything is finished and we have to live with this now.’”
<p>Child is too young or will not understand</p> <ul style="list-style-type: none"> • “Parents usually do not tell their children and ask ‘why do we have to tell them at such a young age’.” • “They feel that their children are too young, for a parent even if a child is 15 years old, they would still feel he/she is too young to understand.” 	<p>Negative impact on child well-being</p> <ul style="list-style-type: none"> • “Some parents would be very adamant and say children’s studies would get impacted” • “The fear of sharing the child’s status is ‘how will the child cope with the understanding that he or she is positive.’”

<ul style="list-style-type: none"> • <i>“They feel that children may not be able to handle the situation.”</i> • <i>“Many times, the parents would say that my child is positive...but he is too young...and in future, we would inform him about his status.”</i> • <i>“Usually they say tell after 12 years.”</i> • <i>“Parents only have misconception that they would not know and understand about it but all children can understand well these days.”</i> • <i>“They felt that the child was too young to know about it and might not understand about the epidemic and some of them felt that child is young and innocent.”</i> 	<ul style="list-style-type: none"> • <i>“The parents think that the child will be shocked and worried about his own health. He may develop some bad feelings for his parents.”</i> • <i>“Their mindset is that if the child comes to know about his status, he will be afraid. They feel that the child is having a happy life and the disclosure may make him nervous and unhappy.”</i> • <i>“Some of them are saying that it need not be told at all and some say that he could complete his 10th as his score would come down.”</i> • <i>“They are worried much about how disclosure would impact the child’s interactions with others.”</i> • <i>“They are worried that the child will talk to peers and other children and that cause the child to be sent away from school.”</i> • <i>“More concern with the health of the girls; tense about menstruation and losing blood.”</i>
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Impact of disclosure on social capital	
Fear child will tell others	Stigma and discrimination
<ul style="list-style-type: none"> • <i>“They also find it very difficult to share it with the child because the child may go and talk about things, with peers that they play with and interact in the village”</i> • <i>“She hesitated to disclose because of fearing they would tell the same to neighbors, school and others and then they would have to vacate their house and would have inability to pay advance payment for rent”</i> • <i>“Parents feel that he child would reveal their status out of anger... so they fear that their reputation in the society may get harmed”</i> • <i>“He may tell his friends...and society may come to know about it...so if they are living in a rented house, they may not be allowed to stay there... the child may not be allowed to play with other children”</i> • <i>“They live in a joint family and there they can hide their own illness...but if the child comes to know about the status, they may not be able to hide it from their relatives, village people.”</i> 	<ul style="list-style-type: none"> • <i>“One of the barriers to disclosure is self-stigma, stigma in community”</i> • <i>“There are lot of cases which come in media where they have been discriminated; children have been removed from the school on the fact that their parents are positive.”</i> • <i>“They have seen the discrimination, they have seen how the people behave with them, and they don't want that to happen with their children.”</i> • <i>“Parents are not willing to disclose due to fear of stigma. And also in case of a girl child they always concerned about her marriage. It is the first thing that comes to their mind: if her status is known to anybody nobody will marry her.”</i> • <i>“If my girl comes out to be HIV+ who will marry her, how will we tell the family?”</i>

Mothers were seen to be more supportive of disclosure. Family structure, including orphan status, also influenced whether a child was most likely to be disclosed to. As shown earlier, sickness in the family was associated with an increase in disclosure.

The NGO played a crucial role in persuading and preparing parents to disclose to children, and communicating to parents that children were likely to already have some knowledge about HIV. Section 4.3 further examines the predictors of disclosure and the characteristics of families who disclose. The psychosocial well-being of children who know their HIV status is examined in Section 4.4. Section 4.5 examines the role parents play in disclosure and Section 4.6 discusses the programmatic focus NGOs place on working with parents.

Characteristics of Families Who Disclose

While qualitative data provided an overview of which factors influence disclosure, quantitative data allows us to determine the predictors of disclosure. Quantitative data collected by CHES and CHELSEA was analyzed to better understand the characteristics of families who disclose.

CHELSEA (North-East Delhi)

Disclosure data was obtained on 82 children at CHELSEA in which 64.6 % (53/82) were disclosed of their own HIV status. More data was available on children’s awareness of their parent’s HIV status, 37.1% (127/342). In order to assess factors associated with child disclosure, we first described the characteristics of HIV+ children in the CHELSEA population (Table 9). Of the children who were disclosed to, 73.6% were male, compared to 46.4% who were not disclosed ($p=0.015$). Children who had been disclosed to had spent about a year longer with the organization, and were older (median age of 11 years in disclosed versus 5 years in non-disclosed, $p<.0001$).

Table 9: Characteristics of Children by Child Disclosure Status, CHELSEA

	Disclosed n = 53 (%)	Non-Disclosed n = 29 (%)	p-value
Housing Type			
Kacha	4 (7.6)	0 (0)	0.40
Semi-pucca	34 (64.2)	20 (69)	
Pucca	15 (28.3)	9 (31.0)	
Gender			
Male	39 (73.6)	13 (46.4)	0.015
Female	14 (26.4)	15 (53.6)	
Age (N, median, range)	52, 11 (6-20)	27, 5 (1-13)	<.0001
Time to ART Initiation (months)	36, 1 (0-6)	8, 0.5, (0-3)	0.87
Time with NGO (years)	4 (1-5)	3 (1-5)	0.95
On ART			
Yes	n=53 40 (75.5)	n=27 9 (33.3)	0.0003
No	13 (24.5)	18 (66.7)	

Disclosure of Parent's Status

We then proceeded to examine the factors associated with disclosure of parental status to children at CHELSEA (Table 10). Similar numbers of boys and girls knew their parent's HIV status (68% v. 50%, $p=0.16$), and of those who were aware they had spent more time with the organization (median time = 4 years for disclosed, 3 years for non-disclosed, $p<0.001$).

Table 10: Characteristics of Children by Disclosure of HIV+ Parent Status to Child, CHELSEA

	Disclosed	Non-Disclosed	p-value
Housing Type (%)	n = 127	n = 215	
Kacha	8 (6.3)	13 (6.05)	0.15
Semi-pucca	100 (78.7)	151 (70.2)	
Pucca	19 (15.0)	51 (23.7)	
Gender (%)	n = 127	n = 211	
Male	64 (50.4)	116 (55.0)	0.41
Female	63 (49.6)	95 (45.0)	
Age (N, median, range)	127, 14, (11-16)	213, 8, (5-11)	<.0001
Time to ART Initiation (months) (N, median, range)	21, 1 (0-6)	11, 0, (0-2)	0.13
Time with Organization (years) (N, median, range)	127, 4 (1-5)	214, 3 (1-5)	0.0007
Child HIV Status (%)	n = 127	n = 215	
Positive	27 (21.3)	24 (11.2)	0.012
Negative/Not Tested	100 (78.7)	190 (88.8)	

Bivariate and multivariate logistic regression models were used to understand predictors of disclosure. Children who were disclosed about their own HIV status were more likely to be male, advanced in their education, older, on ART for their own health, and have a HIV+ parent on ART. Using a multivariate model to adjust for potential confounders, children who were disclosed about their own status were more likely to be on ART and have been disclosed about their parent's status (Table 11). Children who were more likely to be disclosed to about their parent's status had more educated parents, were likely to be HIV infected themselves, disclosed to about their own status and have a parent on ART. When examining parental disclosure with multivariate regression models, parents with higher education were more likely to disclose parental status to children and have a child who is HIV positive. The other factors did not predict disclosure in the model. After taking into account HIV status of the parent and use of ART for the child and parent, gender did not remain a significant predictor of the outcome.

Table 11: Multivariate Model of Disclosure to HIV Positive Children with HIV Positive Parents, CHELSEA

	Child Disclosure aOR ⁺	Parent Disclosure aOR
Housing Type		
Kacha	Ref	Ref
Semi-pucca/Pucca	N/A	0.24*
Female vs. Male child	0.10	1.22
Child HIV+	-	11.56*
Child on ART	13.4*	-
Parent status disclosed	202.23*	
Parent on ART	-	1.25
Parents Education		
Illiterate – class 5	Ref	Ref
Middle school	-	21.55*
Secondary education	-	234.42*
+ Adjusted Odds Ratio *Statistically significant Ref = Reference category		

CHES (Chennai)

Disclosure of child's status

At CHES, 25.2% (39/155) were disclosed of their own HIV status; while 24% (36/150) were disclosed of their parents HIV+ status. There was very little quantitative data available about the disclosure process and who disclosed. Of the 31 cases with data, 80.7% were disclosed to about their own HIV status by their mother, 16.1% by other family members and 3.2% by the father. Children who were disclosed about their own HIV status were more likely to be female (56.4% vs. 43.6%, $p=0.055$) and to be post-pubescent at 14 years old ($p<0.0001$). Orphan status is also a factor of disclosing a child's status, where double orphans were more likely to be disclosed to about their status (48.7%, $p=0.07$) compared to single and non-orphans. Furthermore, children who were on ART for their own health were more likely to be told about their status. This might be the case, since children will ask questions about their health when have to take medication as well as make regular visits to the ART centers. Since income data was incomplete, housing type is used as a proxy to measure the effects of wealth on disclosure status. According to Table 12, children who live in poorer households (*Kacha* style house) were more likely to be disclosed of their own status (39.3%, $p=0.003$).

Table 12: Characteristics of Children by Child Disclosure Status, CHES

	Disclosed n (%)	Not Disclosed n (%)	p-value
Housing Type (%)	n = 34	n = 109	
Kacha	15 (39.3)	18 (23.0)	0.003
Semi-Pucca	10 (28.6)	57 (41.0)	
Pucca	9 (32.1)	34 (36.1)	
Gender	n = 39	n = 116	
Male	17 (43.6)	71 (61.2)	0.055
Female	22 (56.4)	45 (38.7)	
Age (years) (N, median, range)	39, 14, (9-18)	116, 8, (2-16)	<.0001
Time to ART Initiation (months) (N, median, range)	24, 1, (0-9)	32, 1, (0-13)	0.46
Orphan Status (%)	n = 39	n = 116	
Single	11 (29.7)	59 (50.9)	0.07
Double	18 (48.7)	37 (31.9)	
Non-orphan	8 (21.6)	20 (17.2)	
Father's HIV Status (%)	n = 39	n = 114	
Negative	1 (2.6)	9 (7.8)	0.43
Positive	38 (97.4)	105 (91.3)	
Mother's HIV Status (%)	n = 39	n = 115	
Negative	1 (2.6)	2 (1.7)	0.75
Positive	38 (97.4)	113 (98.3)	
WHO Z-Score Cutoffs (%)	n = 29	n = 50	
Severe Thinness	5 (17.2)	4 (8)	0.16
Thinness	3 (10.3)	1 (2)	
Normal	20 (69)	37 (74)	
Overweight	1 (3.5)	7(14)	
Obese	0 (0)	1 (2)	
Child on ART (%)	n = 37	n = 104	
On ART	30 (81.1)	61 (58.7)	0.014
Not on ART	7 (18.9)	43 (41.4)	

Disclosure of Parent's Status

We then proceeded to examine the factors associated with disclosure of parental status to children at CHES (Table 13). Similar to disclosure of their own status, females were more likely to be disclosed to compared to males (58.3% vs. 41.7%, $p = 0.047$) and to be post-pubescent at 14 years old ($p < 0.0001$). Additionally, double orphans were more likely disclosed to of their parents' status (50.0%, $p = 0.066$). Children are more likely to be disclosed of their parents' status while they themselves are on ART (79.4%, $p = 0.026$), where parent's ART status appears to not be a factor of parent disclosure. This latter finding is somewhat contrary to qualitative findings that children ask questions when parents are seen taking medication, and in turn, lead to disclosure. As for the effects of wealth on disclosure, there was

the same finding as for child disclosure – children living in poorer households (*Kaccha* style homes) were more likely to be disclosed of their parents' status (41.9%, $p=0.013$).

Table 13: Characteristics of Children by Disclosure of Parent Status to Child, CHES

	Disclosed of Parent Status	Not Disclosed of Parent Status	p-value
Housing Type (%)	n = 31	n = 107	
Kacha	13 (41.9)	19 (17.8)	0.013
Semi-Pucca	9 (29.1)	55 (51.4)	
Pucca	9 (29.0)	33 (30.8)	
Gender	n = 36	n = 114	
Male	15 (41.7)	69 (61.0)	0.047
Female	21 (58.3)	45 (39.0)	
Age (N, median, range)	36, 14, (11-18)	114, 8, (2-16)	<.0001
Time to ART initiation (months) (N, median, range)	22, 2, (0-9)	33, 1, (0-13)	0.26
Orphan Status (%)	n = 36	n = 114	
Single	10 (27.8)	56 (49.6)	0.066
Double	18 (50.0)	37 (32.7)	
Non-orphan	8 (22.2)	20 (17.7)	
Father's HIV Status (%)	n = 36	n = 116	
Negative	0 (0.0)	10 (8.6)	0.12
Positive	36 (100)	106 (90.4)	
Mother's HIV Status (%)	n = 36	n = 117	
Negative	0 (0.0)	3 (2.6)	1.000
Positive	36 (100)	114 (97.4)	
Father's ART Status (%)	n = 36	n = 116	
ART	6 (16.7)	39 (33.6)	0.0014
Not Applicable	30 (83.3)	59 (50.9)	
Pre-ART	0 (0.0)	18 (15.5)	
Mother's ART Status (%)	n = 36	n = 117	0.95
ART	21 (58.3)	70 (59.8)	
Not Applicable	8 (22.2)	27 (23.1)	
Pre-ART	7 (19.4)	20 (17.1)	
WHO Z-Score Cutoffs (%)	n = 27	n = 52	
Severe Thinness	5 (18.5)	4 (7.7)	0.13
Thinness	3 (11.1)	1 (1.9)	
Normal	18 (66.7)	39 (75)	
Overweight	1 (3.7)	7 (13.5)	
Obese	0 (0.0)	1 (1.9)	
ART Status of Child (%)	n = 34	n = 103	
On ART	27 (79.4)	60 (58.3)	0.026
Not on ART	7 (20.6)	43 (41.8)	

These same factors were included in the bivariate and multivariate models (Table 14). Disclosure was more common in larger families as indicated by the increase in household size; continuing to illustrate that family members do play a role in child disclosure, especially if living in the same house.

Additionally, a child on ART and females were more likely to be disclosed to as well as children that live

in poorer households. When examining disclosure of the parent’s status to the children, similar factors were observed to influence disclosure. Older females were more likely to be disclosed about their parent’s status. Children who were on ART were also more likely to be told about their parents’ status. Surprisingly, children with a parent on ART were less likely to know about their own status and only slightly more likely to know about their parent’s status. This is dissimilar from the WAG...CHELSEA data and inconsistent with the qualitative findings.

Table 14: Multivariate Model of Disclosure to HIV Positive Children with HIV Positive Parents, CHES

	Child Disclosure aOR ^a	Parent Disclosure aOR ^a
Number of people in household	2.99*	2.88*
Housing Type		
Kacha	Ref	Ref
Semi-pucca	0.11*	0.14*
Pucca	0.21*	0.29
Female vs. Male child	3.78*	4.39*
Child on ART	8.13*	6.27*
Parent on ART	0.89	1.30
^a Multivariate model using BMI-for-age-z-score from WHO, Number of people in household, housing type and gender		
*Statistically significant		

The data demonstrates the differences between these two organizations when it comes to disclosing a child’s or parent’s HIV status to the child. CHELSEA beneficiaries were younger (pre-pubescent) males on average in contrast to the CHES beneficiaries who were more likely to be female and post-pubescent. These differences appear to be driven by programmatic choices within the broader different socio-cultural environments of northern and southern India.

Psychosocial Health of Disclosed Children

Both CHELSEA and CHES administered the Strengths and Difficulties Questionnaire (SDQ), a standardized psychometric tool. This questionnaire has 25-scored questions encompassing 5 sub-categories: emotional symptoms, conduct problems, hypersensitivity, peer problems, and pro-social behavior. A total difficulties score is calculated using the sub-scores from the first four mentioned categories. Pro-social behavior, a separate indicator, assesses how well a child socially integrates within the community. In other studies, prevalence of total difficulties score in the abnormal or borderline range for 5-17 year olds was reported at 15.1% in Britain and 20% in Egypt.

CHELSEA (North-East Delhi)

A total of 63 HIV-infected and affected children from CHELSEA were administered the SDQ. Overall, there were 8 (13%) male children reported abnormal or borderline scores and were younger on average than children who posted normal total difficulty scores (7 v. 10, $p=0.004$). With regards to pro-social scores, 36 children posted abnormal or borderline scores and a higher proportion of borderline/abnormal children knew their parent's HIV status. This indicates that children disclosed of their parents' status are having a more difficult time socially compared to those who have not been disclosed. Of the children that were reported with borderline/abnormal pro-social scores, more of them were males and these children were also older (10 v. 9, $p=0.042$).

Table 15: Characteristics of Study Population Stratified by Total Difficulty Score (Among HIV Positive Children), CHELSEA

	Abnormal/Borderline n = 36 (%)	Normal n = 27 (%)	p-value
Disclosure (Child)	30/36 (83.3)	17/24 (70.8)	0.25
Disclosure of parent status (Children of Parents with HIV)	20/24 (83.3)	11/19 (57.9)	0.065
Housing (type)			
Kacha	3 (8.3)	1 (3.7)	0.74
Semi-pucca	22 (61.1)	18 (66.7)	
Pucca	11 (30.6)	8 (29.6)	
Gender	n = 35	n = 27	
Male	27 (77.1%)	18 (66.7%)	0.36
Female	8 (22.9%)	9 (33.3)	
Age (N, median, range)	35, 10 (6-16)	27, 9, (2-13)	0.042
Time to ART Initiation (Months) (N, median, range)	21, 1, (0-6)	14, 0, (0-4)	0.42

Table 16: Demographics of Study Population Stratified by Prosocial Score (Among HIV+ Children), CHELSEA

	Abnormal/Borderline n = 8 (%)	Normal n = 55 (%)	p-value
Disclosure (Child)	6/8 (75)	41/52 (78.9)	1.00 (Fisher's exact)
Disclosure of parent status (Children of Parents with HIV)	4/6 (66.7)	27/37 (73.0)	0.52 (Fisher's exact)
Housing (type)			
Kacha	2 (25)	2 (3.6)	0.07
Semi-pucca	4 (50)	36 (65.5)	
Pucca	2 (25)	17 (30.9)	
Gender			
Male	8 (100)	37 (68.5)	0.06
Female	0 (0)	17 (31.5)	
Age (N, median, range)	8, 7 (6-9)	54, 10, (2-16)	0.004
Time to ART Initiation (Months) (N, median, range)	5, 0, (0-1)	30, 1, (0-6)	0.31

CHES (Chennai)

At CHES, there were a total of 124 infected and affected children that were administered the SDQ, and 24.2% of these children scored an abnormal or borderline total difficulties score. Overall, disclosure did not affect the total difficulties score, and there were no other specific characteristics that were significantly different between children with abnormal and normal scores (Table 17). Only 3.2% (4/124) of the children had abnormal or borderline scores with pro-social behavior, indicating the relatively healthy ability of these children to integrate in their communities.¹

Table 17: Characteristics of Study Population Stratified by Total Difficulty Score, CHES

	Borderline/Abnormal n = 30 (%)	Normal n = 94 (%)	p-value
Children disclosed to about their HIV Status (%)	6 (20.0)	28 (29.8)	0.3
Housing Type (%)			
Kacha	6 (20.7)	21 (24.1)	0.72
Pucca	12 (41.4)	40 (46.0)	
Semi-Pucca	11 (37.9)	26 (29.9)	
People in HH (N, median, range)	30, 4, 3-5	94, 4, 3-7	0.25
Male	19 (63.3)	50 (53.2)	0.33
Age (N, median, range)	30, 9.8, 4-18	94, 10.2, 4-17	0.48
Orphan status (%)			
Single	19 (63.3)	41 (44.6)	0.16
Double	8 (26.7)	31 (33.7)	
Non-Orphan	3 (10.0)	20 (21.7)	

¹ Given the small sample, statistical significance could not be determine

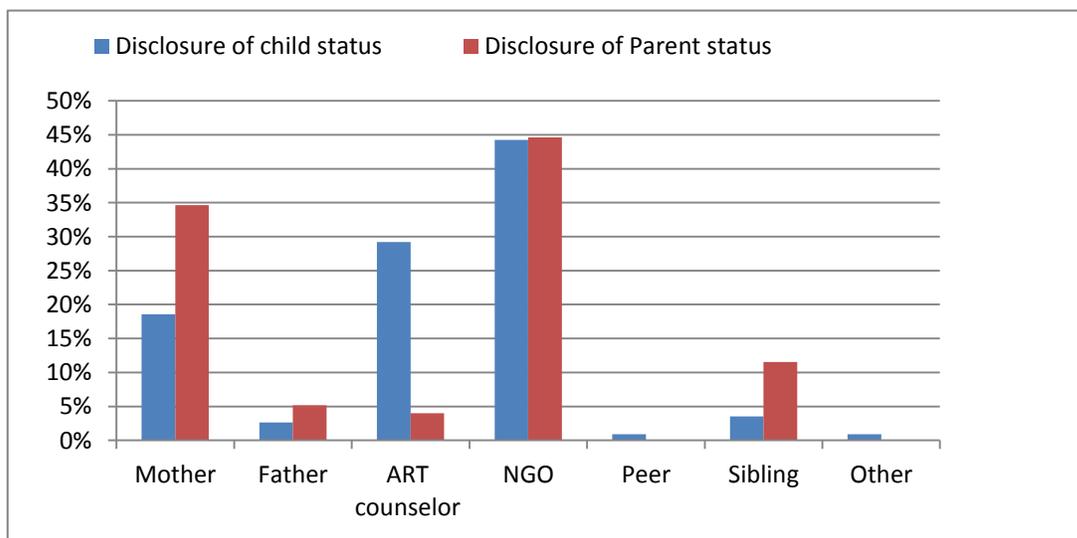
Table 19: Prosocial Scores of Children, CHES

	Borderline/Abnormal n = 4	Normal n = 120
Age (N, median, range)	4, 9.3, (6-13)	120, 10.1, (4-18)
Male (n, %)	3 (75)	66 (55)

Actors involved in the disclosure process

In addition to the factors influencing disclosure, an understanding of the actors involved in the disclosure process and their respective roles allows a more holistic picture of disclosure and contextualizes the work of NGOs. This section examines the role different actors play in the disclosure process as identified by NGO staff. There was agreement in both the qualitative and quantitative data that mothers were the lead actors in the disclosure process. NGO staff identified that little support was provided to parents and caregivers from Integrated Counseling and Testing Centers (ICTC) and ART centers on how to disclose to their children. Furthermore, respondents were rarely able to identify examples of pre and post-test counseling for children in government centers and ART Center counseling for children was also infrequent. This highlights the current importance of both NGOs and parents in disclosure to children. NGOs work in partnership with many of these actors and provide child-centered services which children are otherwise unable to access. Indeed, NGO staff often discussed how their work on disclosure was often led by what a child had been told by other members of their family, school or community.

Figure 4: Actors Involved in Disclosure to Children, CHELSEA



Quantitative data was collected on who disclosed to children receiving care and support services from CHELSEA. Figure 4 shows that the NGO, ART center personnel, and the mother played important roles in

disclosure of child status to the child. The categories are not mutually exclusive and often multiple individuals and institutions played a role in disclosure. This is consistent with other study findings which identify ART initiation as a predictor of disclosure and the catalytic role NGOs play given the reluctance of parents to disclose. Disclosure of parent status was also mostly carried out by the NGO in CHELSEA. Mothers and siblings played a more prominent role in disclosing parent status to children compared to disclosing a child's status. As expected, the role of the ART counselor decreased for disclosure of parental status possibly due to laws on non-disclosure of an individual's HIV status without consent and perhaps a perception that it was not the role of the ART counselor to disclose parent status to children.

While Figure 4 provides an insight into the actors involved in disclosure, this can also be a reflection of programmatic decisions. For example, CHELSEA will disclose directly to a child (after parental consent) while CHES will not, and will instead support the mother or a family member to disclose. Of the 31 cases with data on who was involved in the disclosure process for children receiving services from CHES, 80.7% were disclosed to about their own HIV status by their mother, 16.1% by other family members and 3.2% by the father. In this case, the NGO is not involved in disclosing directly to the child. Therefore, a programmatic decision made by an NGO can significantly change the actors involved in disclosure.

Role of Parents and Siblings in Disclosure

NGO staff felt that single parents were more likely to disclose to the child and had differing opinions about the role education levels of parents and caregivers played in influencing disclosure. The quantitative data appears to associate more parental education with a higher likelihood of child disclosure.

"In the first place, the parents know the problem and have some basic words in the mind. They say that they have lost immunity to disease which their children may have acquired. Then they tell us to take over to tell the exact problem based on the background created by them. From here problem is taken over by us. We know the children know a lot. They relate the posters and pictures and especially when we tell them the stories and anecdotes. They also know that better nutrition can tackle the situation." (CHELSEA)

"In one case, the child was told by grandmother, she said it was an English disease about which she had little information. And we had to tackle the situation accordingly. When we visited after identifying the family, we explained the situation with reference to a virus." (CHELSEA)

Most respondents discussed the role of siblings in the disclosure process. While there were cases where siblings had disclosed to younger siblings, in most cases, siblings were thought to play a role in supporting each other post-disclosure. The dynamics between siblings, including perceived differences in nutrition and care between siblings who were HIV affected and infected was often the cause of tension or disagreement in the family. NGO staff played a role in providing support to family members to address these dynamics.

"Sometimes if the younger one is not aware about the disclosure and the older one is already on ART and all. Then younger one will ask why are you taking this medicine so then they will give the information instead of the parents." (CHELSEA)

"If the sibling is old enough to comprehend and share the information then they do it. I have seen cases where the older siblings, who are above eighteen years, have shared the status." (CCDT)

"If the first child is aware... the siblings would be interacting with each other. So, instead of partial disclosure, it may have been complete disclosure before we approach him." (CHELSEA)

"She has not disclosed to younger brother, she informed to her younger sister that they would have to take care of their brother as he has got HIV, give him medicines regularly and take him to hospital at regular intervals and get CD4 tests." (CCDT)

Role of Friends and Peers in Disclosure

As shown, friends and peers stimulate a child's questions. In a small number of cases, friends and peers were said to play a role in disclosure:

"Friends will tell sometimes, children from infected families and affected families will be there in the same school, there are many chances of children speaking with each other on these issues and get to know."

Respondents focused on the role of friends and peers after disclosure as a form of social support. In residential care homes, friends reminded each to take ART and to eat well. Friends and peers also played an important role in facilitating a child's acceptance of his/her own status and in allowing a child to develop confidence to disclose friends or peers that could trust and felt close to.

Role of ICTC and ART Centers in Disclosure

In government hospitals parental consent is required for an HIV test and care while support and treatment to children is delivered through parents or caregivers. Respondents were unable to identify examples of pre-test counseling for children. If children had not been tested when they were enrolled in NGO programs, NGO counselors would provide pre-test counseling to the children. A child's test result was given to the parents and as the following responses indicate, post-test counseling did not occur for children after the HIV test:

"It is a long queue. They do not do counselling for children' But they do counselling for adults but the quality of counselling is still a question mark."

"In ICTC the counsellors have a social work background...they do the counselling for both adult and children. So many materials are available but none of them use any material. In the private hospital they just take the blood, they don't even tell why they are taking the blood; they just give the report to you. In municipal hospital also, if one is admitted they give a list of tests to be done. HIV test will be one among the list, you just give blood, give it to the laboratory, the result comes out and they show it to the doctor and it is kept in the file. The doctor does not explain."

"They simply give the report and say positive or negative result to the parents."

"The doctor very abruptly tells the parent's HIV status... the doctor just shouts and says that "your mother is positive". That is how children hear about HIV."

Resources for children were minimal and ICTC and ART centers had limited training and a high patient load with little time for in-depth counseling and providing emotion support. Although there were a few examples of individual counselor's using child-friendly practices, in most cases disclosure was felt to be perfunctory and without an assessment of a child or adult's emotional situation and resilience. One respondent described the approach to be 'like a checklist' and 'checklists aren't good for children'. The role of ICTC counselors was to give test reports to parents and refer the child to the ART center. Once a child was put on ART, counseling during routine visits to the ART center was said to focus on the importance of 'eating medicines on time', 'drinking water' and eating well.

"The children who are of more than 5 years or so, they know something from the hospitals that they have to take medicines life time but they do not know that HIV is non-curable or side effects or chances of having OIs...they get information afterwards when they join organizations." (CHELSEA)

NACO Antiretroviral Therapy Guidelines for HIV-Infected Adults and Adolescents Including Post-exposure Prophylaxis recommend disclosure to be assessed during the first patient visit after the HIV diagnosis has been confirmed.⁴⁷

Respondents were divided about whether ICTC centers, ART centers and NGOs should play a key role in facilitating disclosure to the child and supporting parents. However, there was agreement that contact with the ART center was more frequent and that HIV disclosure was rarely linked to testing. With the scale-up of early infant diagnoses, parents will know the status of their children at a much younger age, which may refine the role each institution plays in disclosure. The NACO module on pediatric ART counseling described disclosure as 'the first step in treatment preparedness'.

Given the context and respective roles of family members, caregivers and health care providers, NGOs were the strongest advocates for disclosure and played a crucial role in disclosure. Some respondents believed this was necessary as NGOs were able to build and sustain long-term relationships with families and were therefore best placed to facilitate disclosure. A few respondents felt providing support with disclosure was the primary responsibility of ICTC or ART centers, with a role for NGOs in follow-up after disclosure. However, given the lack of programmatic focus on disclosure in ICTC and ART centers and the strong belief in NGOs about the importance of disclosure, NGOs were the lead actors in introducing and facilitating disclosure.

NGO Approaches to Disclosure

A primary aim of this study is to examine NGO approaches to disclosure and in each case, disclosure programming is embedded in the care and support each NGO provides to children and families. CHES initiated work on disclosure in 2000 when 'nobody talked to the children' and placed an increasing focus on learning what children knew about HIV in 2008. CHELSEA began work on disclosure in 2004 but began implementing disclosure interventions after 2006 when, through Samarth, they initiated a community home-based care program in North-East Delhi. CCDT placed a focus on disclosure in 2007

following the introduction of free pediatric ART in India. SCT runs two residential care homes, one with a population of children between five and thirteen and the other with older children. Disclosure had been initiated in the care home with older children, and although disclosure programming was initiated in 2010, SCT staff were in the process of discussing approaches to disclosure and making programmatic decisions about how best to respond to a child's need to know their HIV status.

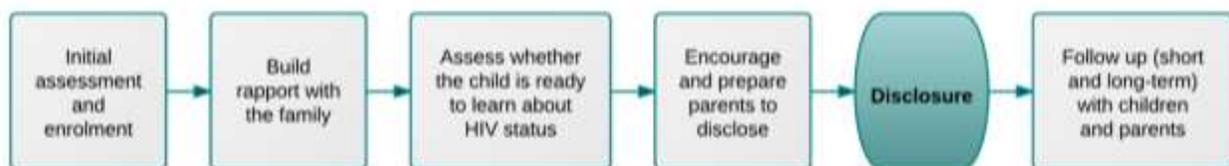
The majority of respondents felt children had a right to know their HIV status and one respondent termed disclosure 'an issue of human dignity'. A child's right to information - about their test result, their body and the tablets they were taking – was cited as a key reason. Disclosure was also considered essential in ensuring a child's active and informed participation in their own health and well-being.

“When you know as to what's happening in your body, the children are much better people to understand what's happening to them and thus be able to care much better for themselves... adolescent children need to know their status because they are very inquisitive and they may experiment...it is extremely important for them to know for their own well-being and the well-being of their partner” (CCDT)

Denying children information by asking them to take unnamed medicines was felt to be unethical, particularly when children were reaching adolescence and sexual maturity and the chances of infecting another person became real. The costs of denying children knowledge of their status was also discussed and respondents felt this could lead to children losing trust in adults or caregivers. However many acknowledged that while disclosure was a right, parents often denied disclosure to their children and that a parent's decision had to be respected, but parents could slowly be encouraged to disclose.

In varying ways, the NGOs follow a similar six-step process (Figure 5) in conducting their disclosure activities. Though it appears linear and sequential graphically, many of the steps occur simultaneously. This section examines each step in greater detail and discusses the similarities and differences between four NGOs in the way counselors and social worker facilitate disclosure and the approaches, tools and resources each organization uses.

Figure 5: NGO Disclosure Process



Initial Assessment and Enrolment

Although many families and children have accessed HIV testing and/or ART services, it is rare for a child to know their HIV status prior to enrolment in the NGOs program. In most cases, counselors and social workers spoke to parents to determine how much a child had been told about his/her status and asked a child open questions about health and sickness to understand how much the child knew.

“Normally when they come for help to us and when we do their registration that time we ask them that have you disclosed your child’s status to the child so they will say no” (CHELSEA)

While each NGO maintained records on each child, whether a child had been disclosed to or not was rarely documented at enrollment. However, CCDT, SCT and CHELSEA had either developed qualitative forms to capture select parts of the disclosure process or integrated collecting qualitative data on disclosure into their existing record keeping system.

Once children and families were enrolled into the program, an initial assessment of needs was conducted. Disclosure to the child was usually not discussed in detail during the enrolment process and during initial home visits. Instead, the focus was placed on assessing the economic status of the family, the health of family members and explaining the services available from the NGO. Residential care programs would often have to provide paperwork to the Child Welfare Committee and make other legal arrangements. Often a child or family would be in crisis or facing economic difficulties and the NGO would prioritize meeting their initial, and most urgent, needs.

Once enrolment was complete, monthly home visits would begin (CHELSEA, CHES, CCDT) in the case of the community based programs, or the child would live in the residential care facility (CHES, SCT, CCDT) and attend the school run by the NGO (CHES, SCT) or attend school in the community (CCDT, CHES). To better understand disclosure, the context of home visits is important. In some cases families are reluctant, especially initially, to invite NGO staff to their homes for fear of stigma in the community. In joint family’s houses with one or two rooms, there is little privacy and counselors and social workers have to be sensitive not only to how much a child knows about the HIV status of family members, but how much other family members know. Secrecy and the fear of stigma are a daily reality in the delivery of home based care and counselors and social workers have to provide care and support in this context or encourage the family or child to come to the NGO.

“Many times it is not structured counselling in home based care program. Even when they are coming to us or walking with us or travelling with us in the bus or on road we do counselling because at home it is very difficult to do the counselling as the other people are around. So it may be in the garden or while walking on the road or maybe she is comfortable coming to the office also, then the counselling happens.” (CCDT)

Residential care programs did not face the same constraints. Children were in contact with caregivers or counselors at all times and regular follow-up was possible; the NGO could closely monitor a child’s nutrition, CD4 count and ART adherence.

If the child has not been tested at the time of enrolment, and one parent was HIV positive, the family was referred for an HIV test. Staff in CCDT, CHES and CHELSEA would seek parental consent for pre and post-test counseling, which was often done without telling the child their status, and often accompany the child and family to the hospital for the test. In the case of residential programs, the child would

often arrive with their HIV test result or the NGO would arrange an HIV test. Notably, the residential care program in CCDT linked disclosure to HIV testing.

"We speak to the referring agency or the relatives to know how much do they know about the child's status or how much does the child know. If the child does not know then the counsellor intervenes and she starts disclosing to the child. If the child doesn't even have an HIV test, then she prepares the child with the pre-test counselling session." (CCDT)

Building Rapport

NGO staff agreed that without building a rapport with the child and family, it was not possible to talk about disclosure; over three to five home visits, the social worker or counselor built a relationship with the child and the family. In residential care homes, counselors would spend time with families or caregivers when the child was first brought to the home, but primarily with children as they settled down in order to better understand their life before enrolment. Games, stories, drawing and listening to the child were cited as strategies to build rapport and counselors highlighted the importance of 'breaking the hierarchy between the adult and the child' (CCDT). A child-centered approach was evident in the way respondents discussed approaches to building rapport with children. A relationship with families was said to be strengthened by showing parents that the NGO is committed to supporting them. Accompanying families and children to the ART Center, gaining their trust, and staying in regular touch all served to build a strong relationship with the family:

We take them to tests and we take care of the needs of children to the extent possible and we win their trust. We immediately rush on a single phone call. When we feel that he wants to talk, we encourage him to tell the details and tell him that his problem will not be told to anyone. (CHELSEA)

We would accompany him to ART centre...we ask him to make drawings... we ask him to express his emotions, his feelings... we ask him to do what he likes ... like he may tell a story...

At first we ask about their likes and dislikes of the child, about the day to day activity and about their happy events and then we give them the next appointment and then we summarize the whole session what we have discussed today." (CHELSEA)

They call me aunt after 3 visits and if there is a provision of phone facility I would contact the by phone (CHES)

During the home visit, once the social worker knows that she has a good rapport with the family, she will ask whether the spouse knows the status or their children know the status and then she will ask whether they want to disclose. First reply she would get is "No". (CCDT)

Without a strong relationship with families, it was considered to be difficult to discuss disclosure or persuade and work with parents to disclose to their children. Building rapport with a child also allowed counsellors and social workers to better tailor care and support to a child's maturity and individual needs.

Assessment of Whether a Child is Ready for Disclosure

During interactions with the child and family, counselors and social workers assessed how much a child knew about HIV and began conversations with parents about whether they felt the child might be ready for disclosure.

“When we are doing disclosure with families, especially in home based care, it takes a lot of time to build a rapport with the entire family with the parents and preparing parents, we have to talk with parents when we are doing individual counselling, we need to know their understanding about the child's emotional state, what will the child do, will the child take this information or not? How do you think the child will react on this? How will they deal with the situation? If the child is angry, what will the child do? If the child is crying, what will they do? So these kinds of preparations happen before the disclosure. More than me a mother will know how her child will react in this situation. Being there with mother and helping her understand what she can do if the child reacts in this way, because she has dealt with the childhood and she knows what can be done in such situations.” (CCDT)

“We ask the child whether he knows or not why he is taking medicines.” (CHELSEA)

“We ask the child ‘do you know why you have come here’? What do you think about this school? Also ask the family whether they have explained to the child why they are here. Most families have not told or explained.” (SCT)

NGO staff often encouraged parents to disclose when they observed a child was asking questions, the parents were frequently sick or the child had started ART. The factors influencing disclosure presented in Section 4.2 also led counselors and social workers to place an increasing emphasis on disclosure.

While assessing whether a child was ready to learn their status was based on observation and informal conversation in most cases, SCT conducted interviews with children to assess their knowledge of HIV, ART, and blood tests for CD4 prior to initiating disclosure and documented the responses given by children.

“What I have learnt with all these is, one we really need to capture the understanding of the child, at the time they come outside and document that and come up with some three or four basic qualitative statements we can make, saying that this is the level of understanding and the child is aware of the disease.” (SCT)

The qualitative interview tool that was developed and used (Table 19) reflected a programmatic decision to respond to the challenge of assessing a child's knowledge of HIV at enrollment and the need to document, and reassess this understanding. The tool also allows for similar data to be collected for all children, and at multiple time points, to capture changes in their understanding of their HIV status to be followed and documented.

Table 18: Program Example - Assessment of a Child's Knowledge and Understanding of HIV (SCT)

Before a session on HIV/AIDS was conducted, each child between the age of nine and thirteen spoke to a teacher or counselor to understand and record how much children knew about HIV and their status.

The following questions were asked:

- Why did you come to this school?
- Why do you take tablets and eat special food?
- What is HIV, ART, CD4?
- What did your parents tell you about your health, about why you were sent to this school? Have you faced discrimination?
- How do you feel when visitors come?
- Why are photos not allowed [in the residential school]?
- Have you noticed many children do not have parents here, what do you think about this?
- What do you dream about your future, what do you want to become?

Several weeks after a session where the children were told their HIV status, the same interview guide was used. SCT found there was not a great change in how much children understood after the session. However, when the same questions were asked a year later, there was a significant change in the understanding children had.

Documenting a child's knowledge allows SCT to develop a disclosure intervention best suited to the information needs of children.

Work with Parents

NGO staff play a crucial role in initiating a discussion on disclosure with parents, preparing a parent to disclose and in supporting parents and caregivers through the disclosure process. As shown in Section 4.2 parents are often reluctant to disclose to children. In the context of community-based care there was consensus that the focus had to be placed initially on working with, and supporting, parents or caregivers both to disclose their own status to the child and/or to disclose the child's status. NGO staff working in the community agreed that parental consent before disclosure was essential and in some cases, written consent was taken from parents before disclosure.

Preparing and Encouraging Parents to Disclose

Encouraging parents to disclose was said to take several weeks to a year in some cases. NGO staff described the process of slowly changing the mindset of parents:

"We will respect that decision but it's our job to slowly-slowly try to convince the parents. Here the child is not a problem...we have to focus more on parents than child". (CHES)

"Parents are really not ready to disclose their status...so we need to work individually with parents to make them understand. We tell them to list down what will happen if they tell the child and what will happen if they don't tell the child. When they see the list, they come to know that there are many

advantages of telling the child and there are few disadvantages which we can still control. They are given examples of other cases without disclosing their names... [We say] if you disclose it to your child, then children can be your strongest support. But parents will take a lot of time. It is difficult to deal with adults when it comes to disclosure.” (CCDT)

NGO staff described the benefits of disclosure and disclosure was presented as a powerful step in equipping a child to deal with the future, take care of themselves, and cope with the loss of parents. The NGO played a key role in addressing parental concerns, alleviating fears and providing practical tools and techniques on how to disclose. CCDT organized support groups for parents as well as three-day family camps where parents could share concerns and discuss strategies for disclosure. Role plays and visual resources are also used to encourage and prepare parents to disclose. The following strategies for disclosure were discussed with parents.

“We help them in the mock sessions and show them how they can use the flip charts. They need not stress about what to say next.” (CCDT)

“We tell the parents/grandparents to have patience and disclose to children with care. We ask them to tell about HIV first. We instruct them to ask children whether they know modes of transmission and ways through which it does not transmit...and ask have they learnt about it in school.” (CHES)

“We tell them to disclose to the children not suddenly but step by step you tell. In the future their questions will be increased and you would have no answers for that. Children will think that their parents do not tell the truth.” (CHELSEA)

“We tell the parents that it is always good to disclose when child wants to know.” (CHES)

Table 19: Program Example - Family Camps (CCDT)

To prepare families for disclosure CCDT conducts ‘Family Camps’. Families who are considering disclosing to their children are identified by social workers and invited to a three day camp. Parallel sessions are conducted for parents and children. Parents are asked to imagine what they would want to communicate to their children if they had to go on a long journey and succession planning is discussed. The advantages and disadvantages of disclosure are debated with parents and parents develop strategies to minimize the disadvantages they perceive. Role plays are used to practice ways to disclose and parents give each other advice and support. Children are given information about how to stay healthy and HIV/AIDS. On the final day, both groups are brought together and some families disclose to their children. Others disclose at home and NGO staff follow-up with parents.

Working with parents in the context of residential care was considerably more challenging since contact with parents or caregivers is intermittent and often parents live in different districts in the state. In the residential programs in SCT and CHES, parents were not seen to be key actors in the disclosure process and parent consent was not considered essential – most caregivers or parents would visit occasionally or collect the children for holidays and were not involved in care decisions.

"I don't think parents find it easier to tell their children, rather they would be more comfortable if institute can take the responsibility to tell their children. And I don't think that any of the parents would have told their child that we are admitting you to this school because you infected with HIV." (SCT)

In contrast, the CCDT residential care program is structured with the aim of reintegrating children with their families after one year, and therefore, parents are involved in the disclosure process, wherever possible.

Absence of Parental Consent

While the NGO works with parents to encourage and prepare them for disclosure, home visits and support to children in the household continue. In the absence of parental consent, counselors and social workers often found themselves in a position where they had to answer questions, explain ART and visits to the hospital for CD4 count without disclosing the child's status. This was challenging and in opposition to the belief that disclosure of HIV status was the right of a child. Furthermore, it was seen to be contradictory to empowering the child to look after themselves and making them an active agent in their own care.

"On one hand we have to hide the fact and on the other we have to ensure that he comes to hospital for tests and takes appropriate medicines." (CHELSEA)

Strategies used included: deflection, providing basic information and avoiding detail, and using 'immunity power' to explain poor health and frequent blood tests. An effort was also made to normalize visits to the hospitals and tablets, i.e. 'mother and father also take tablets'. Interestingly, similar strategies were used to tell the young children their status and often partial disclosure occurred without using the word HIV, even without parent consent. In some cases, terms like CD4 and ART were used but were devoid of context or meaning. As seen in Table 21, information is communicated to children to best persuade them to take medicines, understand that blood tests predict well-being and taking tablets regularly will allow them to perform in school and stay healthy.

Table 20: Explanations Given to a Child in the Absence of HIV Disclosure

Strategies to Explain Illness, CD4 and ART Without Disclosure of HIV status	
<u>Deflection</u>	<ul style="list-style-type: none"> • <i>"He will ask the reason of his illness. Then we tell them not to worry and to pay attention to the studies and hobbies." (CHELSEA)</i> • <i>"It is generally very simple explanation like "you have some illness, you are little weak so you need to be on medication." (CCDT)</i>
<u>Basic Explanation of Immunity Power</u>	<ul style="list-style-type: none"> • <i>"We tell them that all of us have immunity power to fight diseases. But for you it is slightly less and hence you are having frequent problems. We tell them to eat well, take nutritious food." (CHES)</i> • <i>We talk about the falling weight and explain that what is immunity loss and its reasons which lead them to a test called CD4. The child is motivated to know how much immunity power he has now, and that is how we lead him to tests." (CHELSEA)</i> • <i>"We tell them that it [ART] restores immunity power" (CHELSEA)</i> • <i>"If we get a disease our white blood cells will be less and these help increase our immunity power. CD4</i>

is to know about our immunity power.” (SCT)

Medicine for Better Health

- *“We say that it [ART] is for the weakness. By taking this they will not fall ill.” (CHELSEA)*
- *“There is some kind of problem in your blood and doctor has prescribed some kind of tests if the test is not good so then they will put on you some medicines” (CHELSEA)*
- *“If you take medicine, then you will become alright...you will have a good health you can go to school and study well.” (CHES)*

Use of Terms without Explanation

- *“They say my CD4 is good, so I am not taking ART. But they don’t know what CD4 is.” (SCT)*

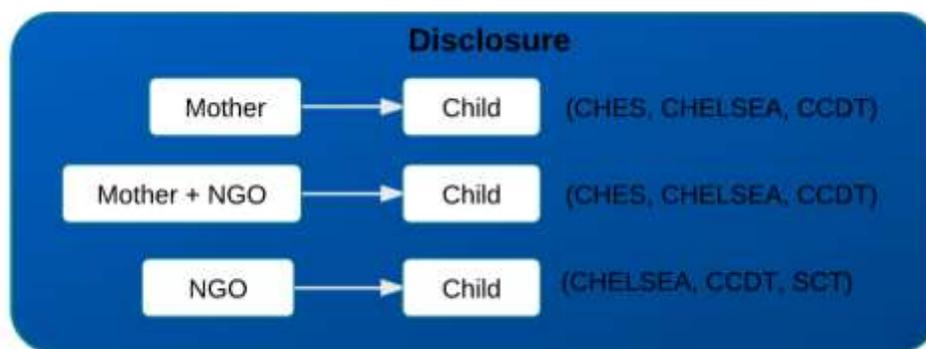
Normalizing

- *“We would show the parents and say even they are taking it for good health, so to keep up could health you also need to take these medicines on a regular time.” (CCDT)*
- *“When we get into bus, they take their water bottles, biscuits, wear shoes; it is a fun trip for them. The day they go to hospital, they have holiday from school.” (CHES)*

NGO support for parents during disclosure

Each NGO made different programmatic decisions about who should disclose to the child and this informed the support they provided to parents and children. All three NGOs providing community home-based care placed a focus on preparing mothers (or caregivers) to disclose. As shown in Figure 6, CHELSEA and CCDT counselors would disclose to children with mothers and caregivers present and the counselors in CHELSEA would disclose to the child without a parent present, after seeking their consent. CHES did not believe the NGO should disclose to the child and therefore would work with children post-disclosure and parents throughout. The differences in programmatic decisions in residential care programs reflect the different approaches and philosophies of the programs.

Figure 6: Programmatic Models to Support Parents During Disclosure



Disclosure

While all four NGOs had developed techniques to tell children their status and support child to understand ART, CD4 and the importance of nutrition, each NGO made different programmatic choices

on how to work with children in the context of disclosure (Table 22). CHES decided it was not the NGOs role to disclose to children while CHELSEA was the only organization providing community based care willing to disclose to a child after seeking consent from a parent or caregiver. In the context of residential care, CCDT disclosed to children individually while SCT conducted a group session to disclose to children. Programmatic decisions about disclosure to children in the CHES residential program were in the process of being made and staff discussed the challenges of disclosing to children, especially since in the context of community-based care, NGO staff encouraged parents to disclose.

Table 21: Programmatic Models to Support Children During Disclosure

NGO	Home-based care	Residential care
CHES	<ul style="list-style-type: none"> • Counselors encourage mothers to disclose to their children and a focus is placed on supporting the mother or caregiver • NGO staff discusses HIV with the child after the mother has disclosed, or with permission, and often play a crucial role in clarifying, explaining and answering questions after disclosure. 	<ul style="list-style-type: none"> • No programmatic decisions made on disclosure to children. • Staff somewhat reluctant to tell children, but follow an ethos of answering children’s questions
CHELSEA	<ul style="list-style-type: none"> • If the mother or caregiver is prepared to disclose, counselors provide support and may disclose to the child with the mother or grandparent. • Counselors disclose to children with the consent of parents. Disclosure occurs over several sessions which are planned in advance (based on the child’s age and knowledge about HIV). • Counselors usually invite children to the Drop-in-Centre the NGO runs to ensure privacy and follow up with the families during and after the disclosure process. 	<ul style="list-style-type: none"> • n/a
CCDT	<ul style="list-style-type: none"> • Counselors encourage mothers and caregivers to disclose to children • In cases where the mother or caregiver requests the NGOs support, the counselor will be present when the mother tells the child. Disclosure is also discussed in support group meetings for caregivers • Families ready to disclose to their children are referred to a three day Family Camp where, in separate groups, parents discuss disclosure and children are prepared for disclosure. Games, roles plays and other techniques are used. 	<ul style="list-style-type: none"> • Disclosure is, wherever possible, linked to testing and a child has an individual session with the before and after their HIV test. • Given that all of the children in the care home are not HIV positive, HIV test results are kept confidential and only select caregivers and the nurse are aware of every child’s HIV status.
SCT	<ul style="list-style-type: none"> • n/a 	<ul style="list-style-type: none"> • Disclosure to older children (10-14 years) in small groups. Two sessions a month to discuss CD4, ART, modes of transmission • Disclosure to older children in one large group with a doctor. The first session was conducted in December 2010

Clarify and Confirm

In cases where parents have disclosed to the child, the NGO plays a role in confirming, clarifying and answering additional questions the child has. In CHES, because the NGO does not directly disclose to the child, their work with the child is primarily focused on post-disclosure follow up and on clarifying information for the child:

“Once the child knows it from parents, they start asking directly us only. They ask ‘Aunty it seems I have this problem. Is it correct? Then we tell them that “yes dear, and if you take these medicines regularly, you will be healthy all through your life”. We tell that that they also have to be careful and take care of mother as well.” (CHES)

In CCDT, where the counselor and parent are often both present during disclosure, the NGOs role is to supplement information provided by the parent and ensure a child receives accurate information:

“In most cases it is parent telling the child, they prefer the counselor when they feel that the counselor can add. We also feel like just ensure that whatever information is passed on to the child is accurate and more than accurate it is the right information which is passed on, even if it is a bit here and there but broadly the right information is passed on. If they say "you be there" then we will be there in the session otherwise they do it. Then we follow up with the parents and the child. (CCDT)

NGOs responded to a child’s individual needs and past experiences. Their support complemented existing support structures in a child’s life, built on information a child may have received from external sources and, in cases where a child did not have access to an adult willing to disclose, the NGO played this role.

Talking to Children about HIV

In all four NGOs, children are given age and maturity-specific information. Three of the four modes of transmission are introduced initially and the fourth, sexual transmission, is typically explained after the child has reached puberty or after 18 years. Often the virus was called a ‘germ’ or a ‘worm’ (*kitanu* or *vishanu* [Hindi], *noi* [Tamil], *kida* [Marathi], *hula* [Kannada]). NGO staff also provides education on nutrition, ART adherence, CD4 count and hygiene. These themes in addition to life skills education are used to develop a child’s understanding of HIV. In CHELSEA, staff highlighted how they would share developments in HIV care with young people.

“HIV is like a small ‘hula’ (worm) which is in your body. It is only in you a little bit and the worms eat the fighting cells and that’s why you get infections. If you don’t eat properly these fighting bodies will decrease so you have to eat, take tablets. Have you seen people with diabetes? They have to have life-long tablets. Similarly, you have to take tablets. If you don’t eat, the virus will increase and so you have to have tablets.”

The ‘body’s energy’, ‘resistance power’, ‘immunity power’ were used to describe the effect of the virus on the body and the word HIV was not used from the outset. In some cases AIDS was introduced and explained and in one case, the fear of AIDS was used to persuade a child to take medicines and look

after themselves. ‘Soldier cells’ was often used to explain the body’s defense against the ‘enemy’ or virus and a military metaphor of attack and defense was often used (Figure 7).

“First of all we talk about HIV infection not about AIDS. We say that it affects energy of the body and it is because of some virus. They ask about virus and we show them the picture of it and tell that its face is changing time to time because it is very clever; we don’t tell them that which type of it is in their body.” (CHELSEA)

“HIV is a little virus that comes in and normally the soldier cell kill the viruses like fever and diarrhoea but HIV is little strong and HIV can fight against the soldier cells and kill them”. (CCDT)

“We also show them different stages starting from HIV and tell that if you will be careful you won’t have to go up to AIDS stage. We show them fearful posters of AIDS and tell them to obey the instructions given by us to avoid such condition.” (CHELSEA)

“If he is educated then I explain him the meaning of HIV and if not I say it is a disease which is breaking your resistance power.” (CHELSEA)

“A virus or the enemy comes in and they attack your soldier cells. This is the pill that you’ll need to take very regularly so that you become really strong and it helps your soldier cells to become stronger. So it would be a very simple language that could be told to a very small child of six, seven or eight years. It also depends on how the child takes about the HIV status”. (CCDT)

“We tell him about white cells in blood as a military to fight the disease, and we tell that they fight the terrorists of any disease.” (CHELSEA)

“We tell them that there is a germ...and if you don’t proper diet, proper medicines and do not maintain our hygiene...the germ would become strong...and it would reduce our strength... for protection against the germ, we have to take proper care.” (CHELSEA)

Figure 7: Flipchart Material to Explain White Blood Cells and ‘Immunity Power’



Source: India AIDS Alliance

In addition to explaining what HIV was, a disclosure conversation had several other functions. Efforts were made during disclosure to normalize HIV and address misconceptions and, in many cases, also disclose the status of the child's parents.

"I would make it clear to him that it doesn't spread by touching someone." (CHELSEA)

"In the process we have to tell them that 'you have got it from your parents and it is not your fault. You are not the only child who has got it.'" (CCDT)

In CCDT disclosure was, wherever possible, linked to post-test counseling:

"If the child is positive then she might not disclose the status at that moment. First she will ask the child 'what do you feel are your results, how do you feel'. She will explain the child once again about transmission and prevention and speaks to the child about HIV/AIDS. Sometimes what happens is, as soon as the children hear the word HIV, they close themselves and feel discriminated and they don't talk to you at all. So they have to be handled very softly and very, very slowly. So it depends again on how the children is taking the session and responding. (CCDT)

Stories, Games and Puppets

Stories, games, puppets and asking a child to draw were all strategies to engage a child and encourage them to express their feelings, concerns or questions. Counsellors and social workers used stories about animals in particular and, as seen below, children are given the opportunity to complete the story with the counsellor.

"I started telling the child a story...mama lion is protecting the baby lions, suddenly some person comes and tries to attack mama lion, and mama lion that day is feeling not too well, she is very tired, and you are quite young, she has to take care of you and take care of other things, sometimes she just cannot get up for hunting. With slightly older children, I tell them to take over the story and build the story with me. I said mummy is very weak, mummy is sick with a particular sickness... I said the name of this illness is HIV... can someone draw for me, he said it looks like this, and then we got into drawing and talking about it, and gradually in one session or two session about how it moves from the body, how it stays in the body, one has to live with it and accept it, and sometimes it brings a whole set of other illnesses, and sometimes it does lead to death and there are times when mummy will not have the energy to hug you, there are times when mummy will be awake and interact with you" (CCDT)

"Sometimes we will give an example of a tiger coming and what happens if the tiger comes near the people. So there are some cells in our body. That is we use creative ideas to tell them about white blood cells and this HIV. Make them understand the difference and what is happening. We will tell them what happens if a tiger attacks, everything gets destroyed. Using these examples we relate it to their body." (CCDT)

"We tell them the story of a monkey who has HIV infection because of the insect. We tell the child that you and your parents have also this infection. They have more faith in their parents. We tell them truth." (CHELSEA)

Respondents in CCDT and CHELSEA discussed making puppets or clay figures to help with disclosure, talk about death and using play techniques to make the situation feel real.

‘Let’s make mummy looks out of clay...I let the child decorate the mother...the child is playing with the clay, touching symbolically, that concretizes, the whole concept for them.’ (CCDT)

‘We will use drawings as puppets. It’s really simple you stick it on a stick and make a face and then give the names to the characters and then you explain the process. (CHELSEA)

Respondents in all four NGOs discussed the use of visual aids and pictures not only during disclosure and to explain concepts, but also before and after disclosure. Drawing was also a way to engage children who were withdrawn or unable to verbalize their emotions. Asking a child to draw was also seen as a tool to better understand a child’s past experiences and hopes for the future:

‘Usually if the child is very young, eight or nine years old and generally seems very upset or not interacting with other children or not interacting with parents, we do use drawing as a method. In that method through a family tree we will find out whom the child is closer to and what are the issues.’ (CCDT)

‘May be during the sessions we draw them when the children are sitting around. You draw and show them what is happening. We draw a soldier and a tiger and tell them what is happening. Here is a tiger, here is the man, what will the tiger do to the man.’ (CCDT)

We tell him that we have an army in our blood which can fight diseases, but when HIV enters, the army becomes weak. Like that we dramatize the situation or tell them to draw (CHELSEA)

‘They would draw a road and we would ask them to put speed breaker to indicate that they had issues in their life like father died at the age of 6 and some sort of issues and we would ask them to ventilate by talking about it and because it would be a disclosure in group.’ (CHES)

‘One child, we asked him to draw what he thought he looked like as a baby, what he looked like now and what he would look like in old age. The difference was that baby had a smile, in today’s picture there was no smile and in the picture at old age there was a small smile. I was shocked at how the child drew this but it shows how children can express feelings through drawing.’ (SCT)

Games were also used to understand how many children knew about HIV in an informal setting and to communicate the importance of self-care. CHES developed a series of games to play with children post-disclosure.

‘We play a game of land mines, where there are landmines are the illnesses, if you bump into one you have to discuss the illness, the precautions you need to take. It might be Malaria or TB or HIV/AIDS ...we understand from them what they understand about HIV/AIDS. That is how we move ahead...building on into modes of transmission, then going on into what are the biases people carry, why do they stigmatize people, why it shouldn’t be done.’ (CCDT)

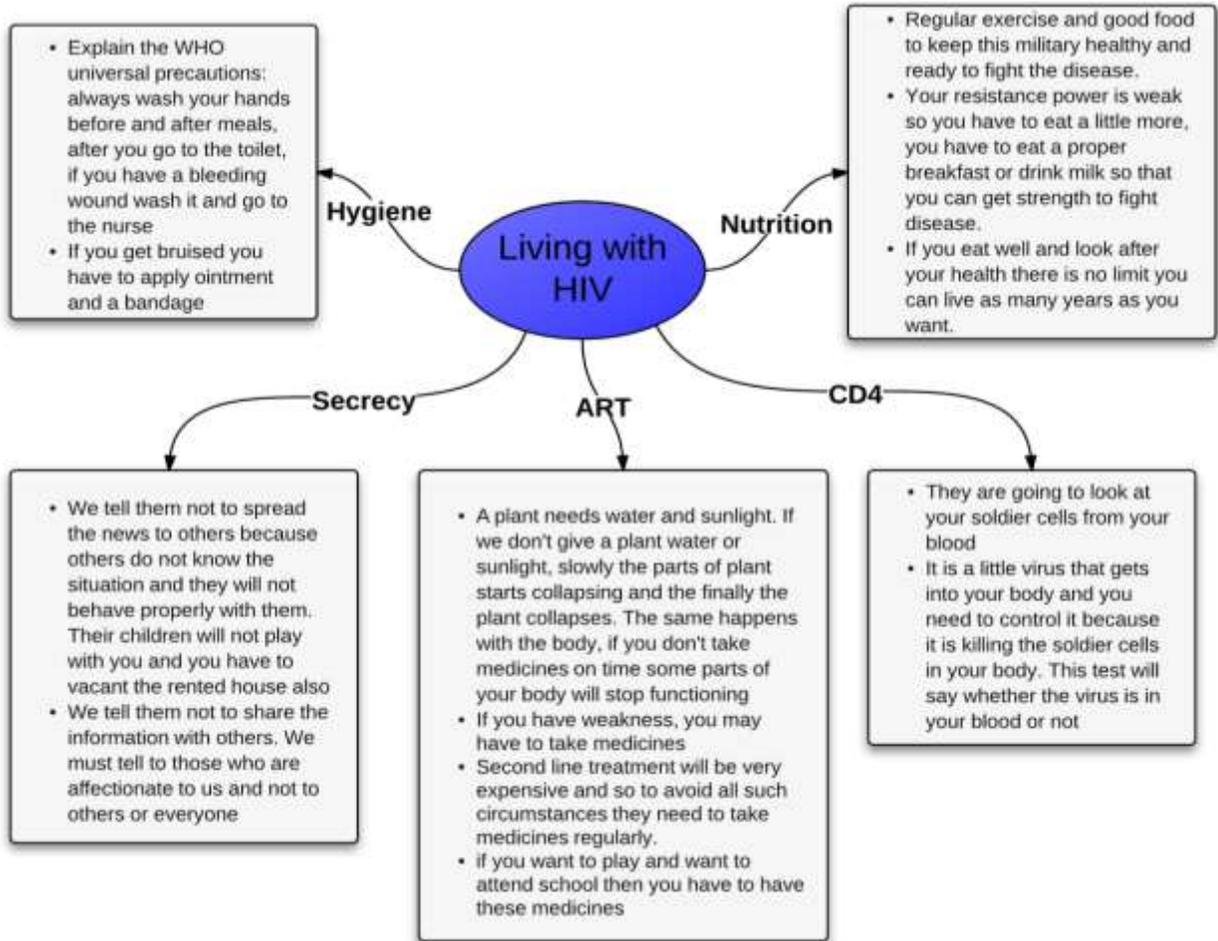
‘I explain to him that just as you have to take care of an egg so that it doesn’t break, similarly now you have to take care of yourself. I tell him that if you have to take an egg and preserve it for 7 days, what would you do? I would give them an egg....and ask him to bring it safely to me after 7 days.’ (CHELSEA)

Living with HIV

A crucial part of disclosure was explaining how a child could stay healthy and what they must do to live with HIV. Often messages about ART adherence, nutrition and hygiene preceded disclosure, were used to explain a child’s HIV status and were re-emphasized after disclosure. Figure 8 shows how the importance of universal precautions, nutrition, ART and CD4 is communicated to children. The use of analogies, stories and metaphors is still significant in communicating with a child. Given parent concerns about a child telling others, secrecy was also emphasised and in some cases children were told to keep

the information secret and in other cases they were asked to consider very carefully who they could trust enough to tell.

Figure 8: Conversations with Children about Living with HIV



Respondents described cases, particularly in residential care, where children would use the information given to them to advocate for their own care, ask for additional food and remind each other to take ART. Children would also remember their own CD4 test dates and the date for collecting ART from the ART Centre.

Children here are so sharp that they themselves come and ask us "Sister I have my CD4 in next 6 months right?" or they will directly ask "sister, when is my CD4 test?". They will also know the dates to bring their ART medicines. They will remind us "Sister tomorrow we are supposed to go to the hospital to get the ART medicines." Many times they tell us before we remind them. (CCDT)

If they don't get a third helping of food and they are hungry – they will say 'madam, you haven't fed me two or three servings, I will lose my health and my CD4 will go down'. One day the meal was late and children said 'madam, we didn't get food on time, we will lose our health and CD4 will come down'. (SCT)

Children reminded each other to take ART and said if they didn't they will lose their health. If a child isn't eating, other children will scare them and threaten to tell the counsellor that the other child isn't eating and therefore not taking ART. Children would say you will lose your health, get lose motions and tomorrow you will have to sleep. (SCT)

Follow-Up

Follow up was felt to be essential to understand the reactions of the child post-disclosure. Where children were living at home, NGO staff communicated with parents post-disclosure to better understand how the child was responding.

"I have to ask the parents whether, after coming home, the child played with other children, whether he watched TV... or whether he sat in seclusion... after getting all this information, when the child comes to visit me next time... I would talk to the child considering the information provided by the parents..." (CHELSEA)

In addition to understanding the initial reactions of a child and supporting the family to address any negative reactions, follow up with parents and children over time was also seen to be crucial. This included: ensuring parents were equipped to provide long term support to the child, and assessing whether the child had absorbed and understood the information provided about how HIV was transmitted, how to take care of themselves and the importance of ART.

"It is usually helping the parent so even if we leave, they are sustainable. They need to be able to address the issues. The whole point is we can do it but we don't want to do it rather the want to empower the parents like what are the questions emerging, are you finding it difficult to answer? So we work with the parents, in case if the parent also points out that the child is having difficulty in accepting the status, then we work with the child also." (CCDT)

Often children would have questions after disclosure and NGO staff would play a role in answering these and supplementing the information given to the child by the parents. As the child matured, conversations between the child and the NGO about growing up, the future and the implications of disclosing to a friend or a partner would become more frequent and NGO staff would support a child through the process of coming to terms with their status over time.

Group Counselling and Social Support

Each NGO had a component of peer support and organized groups for children who were aware of their HIV status. CHES developed a training manual which was used to guide follow-up sessions and all children were referred to *Roja Kuttum* after disclosure.

We conduct group counselling. Children exchange their views there and co-operate with each other giving their examples if one child knows how HIV spreads they discuss with each other... after explaining this to child we ask them to replay as they catch things better...as counsellor we let them do so because children know other children very well. (CHELSEA)

They would come out with open discussion as such what could be done on this problem and everyone would interact with each other for arriving at common consensus solution based on all of their viewpoints. (CHES)

In SCT children were paired with a friend and had sessions with a counsellor and in CCDT children planned and designed the content of their group sessions. SCT also had a buddy scheme where an older child mentored and supported a younger one in daily life; however, this scheme was not currently being used in the context of disclosure. CCDT also had a group for children living in residential care who were on ART to provide peer support after ART initiation and to encourage children to remind each other to take their ART tablets.

Table 22: Program Example - Roja Kuttum (CHES)

Roja Kuttum is a group for children who are aware of their HIV status. CHES developed a training manual for counsellors facilitating this group which was finalized after input from children. Activities focus on explaining the importance of adherence, building resilience and thinking about the future. Games, drawing and group discussions are used in each session.

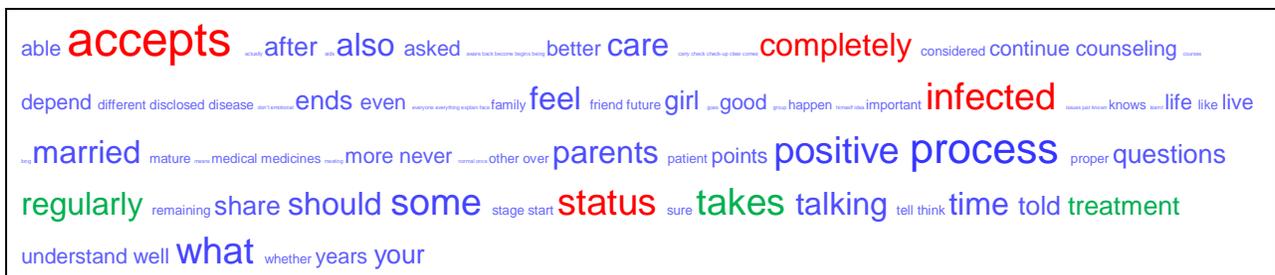
Disclosure complete: Awareness, Acceptance and Self-Care

In order to discuss follow-up post-disclosure, a better understanding is needed of what constitutes disclosure and respondents were asked when they considered disclosure to be complete.

“Have to define the word disclosure...is it just telling them about their HIV status or is it telling them and making them slowly accept and gradually addressing some of their issues by explaining them about the implications and all those things, only when we define the word disclosure, only then we can just draw a line and say that it ends here. Otherwise it should be an on-going process...as our children grow they will have lot of doubts and questions regarding this. Not only about their HIV status but also about how to live the rest of their life and how to manage life.” (SCT)

Figure 9 shows which words were most frequently used when discussing whether disclosure was complete. There was agreement that disclosure was a process instead of a one-off session, however, most respondents did suggest a point at which they considered disclosure to be complete - when ‘the child had accepted he/she has HIV’ and had ‘learned to live with it positively’ - and highlighted the importance of follow up as a child matured.

Figure 9: When is disclosure complete?



Most respondents discussed the process of assessing how much a child understood before determining disclosure to be completed. Adherence to ART and children considering discussing their own status with friends was felt to be an indicator of the child accepting and understanding his/her HIV status.

When we or parents have told him everything and we see that he has correctly and positively accepted it after his questions, we conclude that the disclosure has been meaningful. We see the better care of patient at that stage. We start talking about his future and if response is good, we are satisfied with disclosure process. (CHELSEA)

When child is completely aware of transmission of disease and learnt that he has got HIV and his parents have the same and he is known to have learnt that he would have to take medicines regularly to be better and disclosure becomes complete there. (CHES)

If the child knows about HIV, how it transmits, what the medications are, how to take care of him/herself and has dealt with his emotions. (SCT)

When the child knows about the medical aspects (what is HIV) and accepts it. And, he/she is able to face other people. Child should have the capacity to deal with stigma, questions. This takes time. (SCT)

“When child is completely aware of transmission of disease and learnt that he has got HIV and his parents have the same and he is known to have learnt that he would have to take medicines regularly to be better and disclosure becomes complete there.” (CHES)

“It is not necessary that if the child is told about HIV the disclosure is complete.... it is usually [when] the child accepts one’s own status and learns to live with it positively, that is one we consider the disclosure is complete.” (CCDT)

Table 23: Program Example - ART Club and the Golden Book (CCDT)

The ART club meets monthly in the CCDT residential care home and children take turns to organize and choose a topic for each meeting. The group discussed adherence, self-care and is a form of social support for children. Older children often mentor younger children and the group welcomes new children as they start ART.

Support and Programming for Adolescents

Some respondents felt it was more challenging to disclose to a child during adolescence. NACO guidelines also highlighted disclosure during adolescence as a challenge²⁷ but crucial in the transition from paediatric HIV care to adult care.⁴⁷

“The parents of adolescents who have become infected as infants or young children may find it hard to share the diagnosis of HIV with their children because of fear of stigma or blame from their own children. However, without this knowledge it is impossible for adolescents to progress completely through the transition process into adult care. Sharing this diagnosis with peers is difficult for adolescents who are aware of their HIV status. For these reasons it is especially important that young people:

- *are informed about their HIV status*

- are educated about their condition, its treatment and the importance of adhering to care and ART;
- are confident in their ability to talk about HIV with those whom they want to know about their condition; and
- have a support system so that they know where to obtain help and advice when necessary.”²⁷

All four NGOs were making efforts to address ‘growing up’ and adolescent issues. CCDT runs sessions on sexuality and menstruation and changes in the body for children in residential care. Girls in one of the residential care homes in CCDT requested a session on how to open a bank account and manage their finances and this was incorporated into Life Skills Education sessions. All the NGOs ran sessions on ‘good touch’ and ‘bad touch’. Such programming may not be directly related to disclosure but plays a role in addressing the fact that maturity-specific information is needed even after a child has been told their HIV status.

As children became adolescents and young adults, the question of marriage and child was raised by children and parents. While there was agreement that disclosure to the young adult’s partner was essential and respondents explained how they reiterated this to older adolescents, respondents differed in their opinions on who it was appropriate to marry. Several respondents advised marrying another HIV positive person while others strongly advocated young people living with HIV had the right to marry who they wished and take the necessary precautions.

“Informing them that they are HIV positive and they should get married to only HIV positive person, is a very difficult stage.” (CHES)

“We say that they can marry a person having such disease only who also takes care of himself just like you. We do counselling with parents on this topic. We warn them if you get marry girl and marry her to a normal person he will also be infected and in future her children will also. We assure them that she will get a similar partner. There are people who are working first you get your girl studied and then you can plan their future.” (CHELSEA)

“We don't say ' if you're positive and then marry a positive person only', we would rather say 'you know what you have,' we don't tell them that you have to disclose immediately but we say, 'if you have a partner and if you are getting into a relationship...then definitely you need to disclose your status to the partner.” (CCDT)

Resources and Guidelines

Training and Resources for NGO Staff

Most respondents stated they did not use guidelines regularly. CHELSEA and CCDT referred to the FHI and NACO guidelines on HIV counseling and disclosure and CHES staff referred to the *Roja Kuttum* manual (see Table 23). SCT staff referred to guidelines developed by the Karnataka Health Promotion Trust (KHPT). Several respondents highlighted the challenge of using guidelines:

“We have to work according to their mood. We can't work as per guide-lines only...in the field we have to face different situations and guidelines do not work there.” (CHELSEA)

Mentoring from more experienced staff was seen to be a key resource in CHES and CHELSEA and this included advice on complicated cases and CCDT also used a form of peer mentoring. Social support among staff was a key resource and in many of the organizations, a core team of staff had been present since the organization began work on disclosure.

In CCDT and CHELSEA staff had delivered training to ART and ICTC center counselors on disclosure to children and had developed resources to conduct training.

Policies

CCDT had developed a written confidentiality policy and CHES a child protection policy. While CHELSEA and SCT took steps to ensure confidentiality, this had not been recorded in writing. CCDT had begun work on disclosure guidelines for the organization and while CHES, CHELSEA and SCT had made programmatic decisions on how to facilitate disclosure, this was not available in writing but communicated to staff through training, debriefs and discussion. In CHES flowcharts were used to aid the decision making process when facilitating disclosure. However, there was a lack of focus on creating organizational policies and protocols to facilitate disclosure and train staff, reflective of the focus placed on service delivery.

Reactions Post-Disclosure

The fears and concerns of caregivers outlined in Section 4.2 revealed a perception that disclosure would have negative consequences for a child's health, education, and have a detrimental effect on family relationships, including the respect a child had for a parent. An analysis of parent concerns also revealed a desire to protect the child from harm and concern about how a child would deal with learning their own HIV status or the status of a parent. In actuality, the reported reactions of children after disclosure were not consistent with the reactions parents and caregivers perceived. Figure 10 categorizes the range of responses under key themes and the size of the box is representative of frequency (in many cases reactions were overlapping). Respondents highlighted how most children were accepting of their status or had questions. Crying, or being quiet or withdrawn were described as initial reactions which, over time, were likely to be transformed into acceptance. Often disclosure led to strengthened family relationships and reaffirmed bonds of trust within a family as well as legitimising a child's desire to learn more and ask questions:

"Children start feeling: 'my parents are not hiding anything from me. They have told me everything. They are ready to take care of me.' Sometimes they become the strongest support for their parents. They take their parents to the hospital; see to that their parents take medicine on time. Parents start feeling happy: 'I have disclosed the status now, I was alone but now I have the support. My strongest support is my child.'" (CCDT)

"Children above 14 and 15 years in some cases, when they have come across the disclosure, they would get irritated about why parents could hide this information from them and they would say that this is their right and they should have disclosed already to them and things like that." (CHES)

“Disclosure in my experience has made children understand the disease better because they started ventilating and asking and got cleared about lot of myths in their mind and also this leads them to better health seeking behavior and better ART adherence and children becoming more responsible towards their family.” (CHES)

Figure 10: Reactions Post-Disclosure



As seen in Figure 10, disclosure also led to improved self-care which was also cited by respondents as a reason to tell children their status, and allow them to play an active role in their own treatment. SCT staff described how children would demand additional food and tell staff that without extra helpings their CD4 count would decrease. One respondent compared children who were aware of their status with children who were not and highlighted that children who knew their status were more resilient and better able to conceptualise and cope with their future.

“I have seen both the children who have been disclosed and who have not been disclosed and children who have been disclosed would have clear idea about their future and about the family members whom they have to be with and whom they should live with and who would be caregivers after their parents and children who have not been disclosed would have no idea about these things.” (CCDT)

It is important to recognise that reactions after disclosure could be contingent on how the child found out their HIV status, whether they felt parent’s or others had withheld information from them, and whether they were simultaneously dealing with other life events like the loss of a parent or sickness. In cases where children felt fear, this could be addressed by addressing misconceptions about the virus and assuring children they would not die soon as treatment was available. In one case a child was said to be depressed after disclosure not because being HIV positive scared him, but because he realised he was barred from writing the Indian administrative exam and felt he could no longer fulfil the future he had imagined. The reaction of a child also changes with age, sickness and how other family members respond after disclosure.

“We asked them, how was the experience of their life before and after knowing about HIV. This boy had put it very well in the class that he took the paper and divided his life before HIV and after HIV; he said that he had used all vibrant colors and he would talk well and enjoy with his father, mother, sister and everything who he would be sharing all information that this was before HIV and after HIV, he drew the same house with the tree and a boy sitting in other side of the tree and I asked him who he was, he said that he drew about his status and added even though he knew that his parents were positive and he could

not talk to his parents and he was feeling isolated and he could not talk on this issue to any of my friends...he said that he could not share this issue with anybody” (CHES)

“The status was shared with the child. At that time the child was asymptomatic and the child did not respond or react in a fearful or emotional or break down. Over a period of two years when the child’s health started deteriorating then the question of ‘why me, why my parents’ all those things started emerging. It was not an immediate emotional outburst it was when the child entered symptomatic stage, then the child started realizing how the illness takes a toll on you... going through the experience became very difficult for the child. The child went through that experience and we helped the child and then gradually over a period of some months the child accepted his own status. This was one and a half years after disclosure of the child’s status. (CCDT)

In addition to strengthening family relationships, disclosure can also lead to family members taking better care of each other, included HIV affected children looking after their HIV positive siblings. As one respondent explained, ‘it will affect them equally, it is not only about carrying HIV in your body.’ Indeed, disclosure was described to challenging for a child who was the only HIV negative member of a family and learned all his/her family members were HIV positive.

Respondents felt there were gender differences in reactions post-disclosure. Girls were seen to more accepting of their status and more responsible after disclosure while fewer respondents felt boys would accept their status and described how boys had more questions about girlfriends and sexual maturity as they grew older.

Table 24: Gender Differences in Reactions Post-Disclosure

Explanations Given for Gender Differences Post-Disclosure
<p><u>Girls accept knowledge of their status</u></p> <ul style="list-style-type: none"> • <i>“I have seen girls, especially elder girls taking it more positively and naturally than boys. Girls take it more maturely thinking that “I cannot do anything about it, I am HIV positive and I have to live with it but I have seen others living very happily, so I can also live”, mightier approach than that of the boys. May be the kind of upbringing in the family because girls are always expected to be mightier than boys.” (CCDT)</i> • <i>“The girls are not so worried about it. They have mostly talked about furthering their education and working rather than marriage related issues.” (CCDT)</i> • <i>“Most of the times girls have accepted the status.” (CHELSEA)</i> • <i>“Girls accept faster and boys do not.” (CHES)</i> • <i>“Difficult to handle boys. Girls accept faster and boys do not. Suicidal thoughts among boys are higher. They refuse to take medication.” (CHES)</i>
<p><u>Boys accept knowledge of their status</u></p> <ul style="list-style-type: none"> • <i>“Sometimes boys also accept and they take it causally and they do not make special changes on their behavior and they look as they were earlier.” (CHES)</i> • <i>“Boys were cool and showed no tension.” (SCT)</i>
<p><u>Girls are more responsible</u></p> <ul style="list-style-type: none"> • <i>“Girls became more responsible than boys, boys were also responsible, but girls were more responsible. The girls believed in ART, but boys had lot of myths. “ (CHES)</i> • <i>“Girls mature immediately and they become responsible and they take care of parents and they are very concerned about their parents.” (CHES)</i>

Explanations Given for Gender Differences Post-Disclosure

Questions/concerns about marriage and the future

- *"Often girls ask us that if marriage is possible or not." (CHELSEA)*
- *"Girls never thought of marriage after they knew that they were HIV positive, but boys started to talk about marriage." (CHES)*
- *"Girls are more worried about their looks because sometime they do get side effects and if they are not beautiful and plus they have HIV they think nobody will come to us." (CHELSEA)*
- *"Some girls, because they had seen their mothers (some children's mothers were staying there), worrying were upset by it." (SCT)*
- *"Boys are more worried, they doubt if they kiss their girlfriend will they transmit HIV to their girlfriend. Another boy who wants to get married and is positive asked us if he can get married and whether he can disclose his status. The girls are not so worried about it. They have mostly talked about furthering their education and working rather than these kinds of marriage related issues. Most of these questions are from boys. I guess as they grow older the boys get attracted and want to have girl friends at an earlier age as compared to the girls. So the boys are asking more questions these days." (CCDT)*
- *"Boys get attracted and want to have girl friends at an earlier age as compared to the girls. So the boys are asking more questions these days. For girls, the counsellor had a session with them about sexuality and menstruation and they asked a lot about condoms and precautionary measures for sexual intercourse." (CCDT)*
- *"In terms of emotion reactions also. I don't say that they don't cry, but I have seen boys crying a lot after knowing about their status. They start fighting. Fighting in the sense, "why did it happen to me?" (CCDT)*

CONCLUSIONS

The purpose of this study was to examine three research questions on disclosure programming and the outcomes of disclosure to children living with, and affected by, HIV:

1. What are the characteristics of families who disclosed the child's HIV status or the parent's HIV status to the child?
2. What programmatic choices have NGOs made to facilitate disclosure?
3. Are disclosed children psychosocially healthier than children who were not disclosed to as measured by the Strengths and Difficulties Questionnaire (SDQ)?

This study used a mixed-methods approach to examining disclosure based on four NGOs in high-prevalence states in India. This entailed using a) in-depth interviews with NGO staff providing and coordinating disclosure interventions, and b) quantitative program data from two NGOs on disclosure to children living in the community, including scores from the SDQ to better understand psychosocial well-being. Disclosure was defined as telling a child their own HIV status and/or the HIV status of their parents.

Predictors of Disclosure

Our results suggested that disclosure was not readily made by a parent. Rather, disclosure was a decision made by a parent when the physical, social, psychological and economic consequences of experiencing HIV/AIDS became increasingly significant in the family. Furthermore, disclosure also became a parental decision when withholding information from a child became increasingly difficult, or, as the NGO encouraged a parent to disclose. This is consistent with the finding that ART initiation was the strongest predictor of disclosure, albeit lagged in time. As NGO staff explained, the concept of disclosure was rarely introduced by parents, and thus it most often had to be raised by the NGO. The qualitative data highlighted that the sickness of parents and children and, the quantitative data revealed a child's sex, as well as the education level of the parents, to be significant predictors. Both the qualitative and quantitative data highlighted the role of age and maturity in influencing disclosure. Given the occurrence of partial disclosure and the fact that children assimilate knowledge from various sources, a child is likely to find out their status as they mature, independent of parent's decision to disclose. Denying disclosure can often be tantamount to disallowing the child to voice their questions, fears and knowledge of HIV due to self-stigma. There was strong support in the data that parents should be the lead actors in disclosure, guided by the child's maturity, and supported by a health care worker. This is also echoed in the NACO guidelines.

The event of an HIV test was not a predictor of disclosure to children, indicating that the patterns of disclosure for children do not fit into the model of pre-test and post-test counseling used for adults. In the CCDT residential care home, disclosure was, wherever possible, linked to testing. However in most cases, families were either enrolled into the program after the HIV test or denied permission to disclose

to the child. This also explains the finding that ART was the strongest predictor of disclosure and with the scale-up of Early Infant Diagnosis this trend is likely to continue. The implications of this finding on the role of multiple institutions (ART centers, ICTC and NGOs) in facilitating disclosure need to be examined in more detail.

The quantitative data highlighted the effect of programmatic decisions on patterns of disclosure. In CHELSEA, boys were more likely to be aware of their status than girls and in CHES, girls were more likely to be aware. The age of the child at disclosure also was strongly influenced by programmatic decisions. For instance, CHELSEA was open to telling children at a younger age and is willing to disclose to the child after seeking parent consent; whereas, CHES believed in working solely with caregivers, which contributes to the fact that the median age of disclosure for their beneficiaries is 14 years.

NGO Programming

NGOs were the strongest advocates of disclosure and utilized a child centered approach to their work with children. There was a greater focus on counseling on ART adherence, nutrition, hygiene and self-care than there was on providing psychosocial support to children. CCDT staff discussed psychosocial support more frequently than other respondents.

Each NGO developed disclosure interventions in response to the fact that children were living longer and could access treatment or integrated a focus on disclosure into existing community-based and residential care programs. These interventions were developed based on what each NGO itself considered good practice, with input from experts in some cases as well as existing FHI guidelines⁴⁴; in others. While children's own voices influenced post-disclosure follow up, life-skills education, group counseling sessions, and interventions had been adjusted based on questions and responses from children and caregivers. However, neither group was consulted in a detailed way when interventions were being developed. This was also reflective of the fact that when each NGO began work on disclosure it was an area which had previously receive little focus and attention.

Over the last five years each NGO has developed expertise in designing and implementing disclosure interventions. There has been a greater focus placed on service delivery and, as a result, each NGO has gained expertise in training their own staff and currently have a team of staff with significant experience in working with parents and children on disclosure. The development of disclosure protocols, policies and monitoring and evaluation frameworks to improve data collection and the use of this data to make informed decisions has, however, been significantly slower. Nonetheless, developing such tools is likely to be the next stage of organizational growth for NGO disclosure programming and capacity building in this area, which could be of further benefit to an NGO's capacity to deliver disclosure services more effectively.

Given the limited programmatic knowledge on disclosure in India, our results suggest a need to more widely share the experience and expertise of NGOs which have already made significant progress in designing and implementing disclosure programs. This includes, but may not be limited to: supporting

these NGOs to train and mentor other NGOs on how to facilitate disclosure. The national response would benefit greatly if additional resource were made available that would allow NGOs to document their approaches used to facilitate disclosure, the strategies employed for training new staff, and how they confronted the challenges of working on disclosure. Given the scarcity of knowledge on disclosure, it is crucial that the experience and expertise these NGOs be used to inform new disclosure programming and relevant policy.

Data on Disclosure

The study shows that there is a need for more and better quality data (including longitudinal information) to track progress more consistently as well as document lessons learned. This could include qualitative data on the disclosure process as well as quantitative data on disclosure, health outcomes and psychosocial well-being. The benefits of collecting high quality data in a replicable way are numerous:

- a) Allows health care workers to use up to date information to make decisions,
- b) Allow successes and challenges to be documented,
- c) Increases the consistency of service delivery
- d) Potentially improves the way health care workers are trained and mentored,
- e) Informs future program decisions on disclosure in other NGOs and in government facilities,
- f) Used to conduct impact evaluations on disclosure interventions.

Improved monitoring frameworks and data collection will have a positive effect on other services the NGO provides to children. In assessing next steps for NGO capacity building and improved disclosure programming, developing robust data collection frameworks, which are owned by the organization and developed to meet NGO service delivery and decision making needs, should be a priority.

Psychosocial Well-being of Children

The study shows that disclosure does not have a negative effect on the psychosocial well-being of children. This also reveals that the perceptions about disclosure are different from actual outcomes and reaffirms the role NGOs play in persuading parents to disclose and the importance of disclosure.

Study Limitations

While this cross-sectional study provides insights into factors with influence disclosure, the psychosocial well-being of children who are aware of their status, and different disclosure interventions, it was not designed as an impact evaluation. Therefore while the study was able to advance knowledge on disclosure approaches, it was not able to scientifically evaluate each intervention to assess effectiveness. We used was routine quantitative program data and therefore a comparison across NGOs was challenging due to data scope, consistency and quality limitations. Two of the NGOs in the study did not have any usable quantitative data on disclosure. While the study provides insight into the disclosure process, a well-designed evaluation framework developed for these programs using a larger

and more representative sample of NGOs and a greater number of interviews would have produced a deeper and richer understanding of disclosure interventions.

Implications for Further Research

Given the scarcity of research on disclosure in India, further research is needed on disclosure in the context of community-based care, residential care and ART centers. The latter is crucial, particularly as it is unlikely that the majority of children living with and affected by HIV have access to NGO support. More research based on interviews with caregivers, mothers and children is also needed to complement data on the challenges health care workers face in facilitating disclosure. Additional mixed methods studies which go beyond determining the patterns and frequency of disclosure to examine: a) health outcomes and psychosocial well-being of children and caregivers over time, and b) the nature of disclosure and approaches used will provide a more detailed insight into the predictors and outcomes of disclosure. Longitudinal studies with children and mothers also provide an opportunity to better understand how a child's understanding of HIV develops and changes as they become adolescents and adults. Finally, community and facility level outcome and impact evaluation research, especially with cost data, is also scarce and would allow interventions to be evaluated more fully and the information generated could more readily be used to improve policies and programs.

National Context

In 2006, the National AIDS Control Program introduced free pediatric antiretroviral in India, increasing the number of HIV positive children surviving into adulthood.^{10,11} India has recognized the need for improved programming for children and adolescents living with, and affected by, HIV and efforts have been made to scale-up access to pediatric ART. The NACO Guidelines recommend disclosure to a child during treatment preparedness and suggest the caregiver should be prepared for disclosure. The NACO Pediatric Counseling Training Module provides the following information on disclosure:

“Counseling for disclosure is an ongoing process and the health care provider needs to work with the child on every visit. Ideally the caregiver should be the one to disclose information to the child. Disclosure to children should be done little by little, encouraging questions, providing truthful answers, and making the child understand they can come back with more questions at any time. Counseling the caregiver for guidance on disclosure of HIV status is important component of the counseling process. Counseling techniques used should be individualized, based on the child's age, maturity, clinical and social circumstances; and should facilitate the child's capacity to cope with their illness.”

This recommendation is in-line with study findings and other good practice, however, implementation and mainstreaming has been challenging and findings showed that ICTC and ART centers currently are unable to provide counseling services to children and were often uninvolved in the disclosure process, or disclosed without following the recommendations above.

Future Directions for Disclosure Programming

Based on study findings and recommendations given by respondents, the following recommendations should be considered to further develop disclosure programming:

1. **Build and/or strengthen state institutional capacity, particularly at the ART centers, to improve the provision of care and support to mothers/caregivers and children in the disclosure process:** ART Centers should integrate into their service standards a much stronger focus on child disclosure counseling, including stronger collaboration and support for parents/caregivers. ART Centers should train counselors and monitor their work quality.
2. **Build and/or strengthen NGO capacity to support or undertake disclosure activities:** NGOs should continue to facilitate linkages with hard-to-reach populations and be prepared and trained to provide disclosure counseling services to families that cannot or will not access services through the state institutional settings. These services should be based on clear organizational guidelines and policies with child-centered care plans. NGOs need to provide on-going support and mentoring to counselors and social workers who work with children and families.
3. **Expand and update national guidelines, informed by the global experience, on pediatric disclosure and develop a toolkit on child disclosure:** These guidelines should be created in a participatory manner with key stakeholders – such as the State AIDS Control Society (SACS), NGOs, and other institutions that have an expertise in child psychology and HIV. These guidelines could include, good practices, clarification on questions around disclosure, and child-friendly resources (stories, games, visuals) for discussing HIV with children and disclosing their own or family members' status.
4. **Based upon the updated national guidelines, develop training modules and resources on disclosure:** These materials should to be differentiated to meet the needs of ART center personnel, NGO staff and caregivers. The training modules should be available in local languages.
5. **Develop a robust monitoring and evaluation process:** Develop and maintain a child-centered routine information system of the counseling and disclosure process. The identification of appropriate outcome measures of the well-being of the children and families is essential to conduct impact evaluation studies. Using well collected routine program data will allow for evaluation research to measure outcomes and impacts over time as the programs develop. Improved documentation will ensure institutional memory, continuity of service delivery in case of staff turnover and will allow the quality of services provided to be monitored and improved.

As HIV positive children reach adolescence, the public health significance of disclosure increases especially as young people begin to take a more active role in decisions about their own health, often

become caregivers for their ill parents or siblings, and increasingly become sexually active and risk spreading the disease to their sexual partners.^{14,35,36} For some respondents disclosure was a 'question of human dignity' and a 'right of the child to know the truth' and for others disclosure was an inevitability. In either case, disclosure was seen as necessary and facilitated by parents with support from health care providers in a proactive way, instead of allowing a child to find out. There was agreement that disclosure would lead to improved well-being, adherence and, in most cases, strengthened relationships within the family, which is also confirmed by existing research on disclosure. Parents too were said to be relieved after disclosure and existing research also shows that disclosure often reduces the pressure on parents to treat HIV status as a 'secret'. As one respondent explained, 'it is not just about having HIV in the body.' Disclosure therefore does not only impact the 100,000 children living with HIV in India, but the children affected by HIV, their parents, caregivers and families.

WORKS CITED

1. Anon. *Global Report: UNAIDS Report on the Global AIDS Epidemic 2010*. 2010.
2. Ghanashyam B. India failing children orphaned by AIDS. *The Lancet*. 2010;375(9712):363–364.
3. Bhattacharya M, Dubey AP, Sharma M. Patterns of Diagnosis Disclosure and its Correlates in HIV-Infected North Indian Children. *Journal of tropical pediatrics*. 2011;57(6):405-11. Available at: <http://tropej.oxfordjournals.org.ezproxy.bu.edu/content/early/2010/12/09/tropej.fmq115.full>. Accessed December 13, 2011.
4. Butler AM, Williams PL, Howland LC, et al. Impact of Disclosure of HIV Infection on Health-Related Quality of Life Among Children and Adolescents With HIV Infection. *PEDIATRICS*. 2009;123(3):935-943. Available at: <http://pediatrics.aappublications.org/cgi/doi/10.1542/peds.2008-1290>.
5. El-Sadr W, Rabkin M, Abrams EJ. *Columbia Clinical Manual Volume 1.0: Pediatrics*. New York: Columbia University; 2004.
6. Gerson AC, Joyner M, Fosarelli P, et al. Disclosure of HIV diagnosis to children: When, where, why, and how. *Journal of Pediatric Health Care*. 2001;15(4):161-167. Available at: <http://www.sciencedirect.com.ezproxy.bu.edu/science/article/B6WKK-45WHVB7-H/2/48eb47a221900c1b6b5a63a201f7bd64>. Accessed January 6, 2011.
7. Ishikawa N, Pridmore P, Carr-Hill R, Chaimuangdee K. Breaking down the wall of silence around children affected by AIDS in Thailand to support their psychosocial health. *AIDS Care*. 2010;22(3):308-313. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/20390510>. Accessed April 18, 2011.
8. Murphy DA, Marelich WD, Hoffman D, Steers WN. Predictors of antiretroviral adherence. *AIDS Care*. 2004;16(4):471-484. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/15203415>. Accessed November 23, 2011.
9. Bikaako-Kajura W, Luyirika E, Purcell DW, et al. Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS and Behavior*. 2006;10(4 Suppl):S85-93. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/16791525>. Accessed April 18, 2011.
10. Murphy DA, Armistead L, Marelich WD, Payne DL, Herbeck DM. Pilot trial of a disclosure intervention for HIV+ mothers: the TRACK program. *Journal of Consulting and Clinical Psychology*. 2011;79(2):203-214. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/21355637>. Accessed November 2, 2011.
11. AAP. Disclosure of illness status to children and adolescents with HIV infection. American Academy of Pediatrics Committee on Pediatrics AIDS. *Pediatrics*. 1999;103(1):164-166. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/9917458>. Accessed March 1, 2011.
12. Xu T, Wu Z, Rou K, Duan S, Wang H. Quality of life of children living in HIV/AIDS-affected families in rural areas in Yunnan, China. *AIDS Care*. 2010;22(3):390-396. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/20390520>. Accessed April 18, 2011.

13. Mellins CA, Brackis-Cott E, Dolezal C, et al. Mental Health of Early Adolescents from High-risk Neighborhoods: The Role of Maternal HIV and Other Contextual, Self-Regulation, and Family Factors. *2008;33(10):1065-1075*. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2734120/>.
14. Lipson M. Disclosure of diagnosis to children with human immunodeficiency virus or acquired immunodeficiency syndrome. *Journal of Developmental and Behavioral Pediatrics: JDBP*. 1994;15(3 Suppl):S61-65. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/8063922>. Accessed January 6, 2011.
15. Arun S, Singh AK, Lodha R, Kabra SK. Disclosure of the HIV infection status in children. *Indian Journal of Pediatrics*. 2009;76(8):805-808. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/19802549>. Accessed January 6, 2011.
16. Dematteo D, Harrison C, Arneson C, et al. Disclosing HIV/AIDS - to children: The paths families take to truth-telling. *Psychology, Health & Medicine*. 2002;7(3):339. Available at: <http://www.informaworld.com.ezproxy.bu.edu/10.1080/13548500220139395>. Accessed March 27, 2011.
17. Kennedy DP, Cowgill BO, Bogart LM, et al. Parents' Disclosure of Their HIV Infection to Their Children in the Context of the Family. *AIDS and Behavior*. 2010;14:1095-1105. Available at: <http://www.springerlink.com/index/10.1007/s10461-010-9715-y>. Accessed November 12, 2011.
18. Blasini I, Chantry C, Cruz C, et al. Disclosure model for pediatric patients living with HIV in Puerto Rico: design, implementation, and evaluation. *Journal of Developmental and Behavioral Pediatrics: JDBP*. 2004;25(3):181-189. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/15194903>. Accessed April 18, 2011.
19. Callens SFJ, McKellar MS, Colebunders R. HIV care and treatment for children in resource-limited settings. *Expert Review of Anti-Infective Therapy*. 2008;6(2):181-190. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/18380600>. Accessed January 6, 2011.
20. Ionescu C. Romanian parents keep HIV a secret from infected children. *Lancet*. 2006;367(9522):1566. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/16703676>. Accessed April 18, 2011.
21. Instone SL. Perceptions of children with HIV infection when not told for so long: implications for diagnosis disclosure. *Journal of Pediatric Health Care: Official Publication of National Association of Pediatric Nurse Associates & Practitioners*. 2000;14(5):235-243. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/11005886>. Accessed March 1, 2011.
22. Chaturvedi VM, Vijay K. *Facilitating Testing and Disclosure for Children and Adolescents*. 2009.
23. Domek GJ. Debunking common barriers to pediatric HIV disclosure. *Journal of Tropical Pediatrics*. 2010;56(6):440-442. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/20185559>. Accessed January 6, 2011.

24. Klitzman R, Marhefka S, Mellins C, Wiener L. Ethical issues concerning disclosures of HIV diagnoses to perinatally infected children and adolescents. *The Journal of Clinical Ethics*. 2008;19(1):31-42. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/18552051>. Accessed March 27, 2011.
25. Wiener LS, Battles HB, Heilman N, Sigelman CK, Pizzo PA. Factors associated with disclosure of diagnosis to children with HIV/AIDS. *Pediatric AIDS and HIV Infection*. 1996;7(5):310-324. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/11361489>. Accessed January 6, 2011.
26. Arun S, Singh AK, Lodha R, Kabra SK. Disclosure of the HIV infection status in children. *Indian Journal of Pediatrics*. 2009;76(8):805-808. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/19802549>. Accessed January 6, 2011.
27. NACO. Guidelines for HIV Care and Treatment in Infants and Children. 2006. Available at: http://www.nacoonline.org/About_NACO/Policy__Guidelines/Policies__Guidelines_Table_for_download/. Accessed March 28, 2011.
28. Anon. UNICEF India - HIV/AIDS - HIV/AIDS. Available at: http://www.unicef.org/india/hiv_aids.html. Accessed March 2, 2011.
29. NACO. Department of AIDS Control Ministry of Health & Family Welfare Annual Report 2010-11. 2011.
30. Anon. National AIDS Control Organisation. Available at: http://www.nacoonline.org/About_NACO/. Accessed March 27, 2011.
31. Vreeman RC, Nyandiko WM, Ayaya SO, et al. The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS Patient Care and STDs*. 2010;24(10):639-649. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/20836704>. Accessed March 2, 2011.
32. Vaz LME, Eng E, Maman S, Tshikandu T, Behets F. Telling children they have HIV: lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS patient care and STDs*. 2010;24(4):247-56. Available at: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2864057&tool=pmcentrez&rendertype=abstract>. Accessed December 13, 2011.
33. Qiao S, Li X, Stanton B. Disclosure of Parental HIV Infection to Children: A Systematic Review of Global Literature. *AIDS and Behavior*. 2011. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/22016331>. Accessed November 9, 2011.
34. Kallem S, Renner L, Ghebremichael M, Paintsil E. Prevalence and Pattern of Disclosure of HIV Status in HIV-Infected Children in Ghana. *AIDS and Behavior*. 2010. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/20607381>. Accessed January 6, 2011.
35. Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV diagnosis to Children: History, Current Research, and Future Directions. *Journal of developmental and behavioral pediatrics : JDBP*. 2007;28(2):155-166. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2440688/>.

36. Vijayan T, Benin AL, Wagner K, Romano S, Andiman WA. We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. *AIDS Care*. 2009;21(10):1222-1229. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/20024697>. Accessed March 1, 2011.
37. Bhattacharya M, Dubey AP, Sharma M. Patterns of Diagnosis Disclosure and its Correlates in HIV-Infected North Indian Children. *Journal of Tropical Pediatrics*. Available at: <http://tropej.oxfordjournals.org.ezproxy.bu.edu/content/early/2010/12/09/tropej.fmq115.abstract>. Accessed January 6, 2011.
38. Kouyoumdjian FG, Meyers T, Mtshizana S. Barriers to Disclosure to Children with HIV. *Journal of Tropical Pediatrics*. 2005;51(5):285 -287. Available at: <http://tropej.oxfordjournals.org.ezproxy.bu.edu/content/51/5/285.abstract>. Accessed January 6, 2011.
39. Myer L, Moodley K, Hendricks F, Cotton M. Healthcare Providers' Perspectives on Discussing HIV Status with Infected Children. *Journal of Tropical Pediatrics*. 2006;52(4):293 -295. Available at: <http://tropej.oxfordjournals.org.ezproxy.bu.edu/content/52/4/293.abstract>. Accessed January 6, 2011.
40. Oberdorfer P, Puthanakit T, Louthrenoo O, et al. Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. *Journal of Paediatrics and Child Health*. 2006;42(5):283-288. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/16712559>. Accessed January 6, 2011.
41. Wiener LS, Battles HB, Heilman N, Sigelman CK, Pizzo PA. Factors associated with disclosure of diagnosis to children with HIV/AIDS. *Pediatric AIDS and HIV Infection*. 1996;7(5):310-324. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/11361489>. Accessed January 6, 2011.
42. De Baets AJ, Sifovo S, Parsons R, Pazvakavambwa IE. HIV disclosure and discussions about grief with Shona children: A comparison between health care workers and community members in Eastern Zimbabwe. *Social Science & Medicine*. 2008;66(2):479-491. Available at: <http://www.sciencedirect.com.ezproxy.bu.edu/science/article/B6VBF-4R003WS-2/2/92cd4736a0894423c47a601421514c57>. Accessed January 6, 2011.
43. Anon. Training Modules. Available at: <http://www.columbia-icap.org/Modules/>. Accessed January 6, 2011.
44. Family Health International [FHI] India. *Protocol for Child Counseling on HIV Testing , Disclosure and Support*. 2007.
45. Gerson AC, Joyner M, Fosarelli P, et al. Disclosure of HIV diagnosis to children: When, where, why, and how. *Journal of Pediatric Health Care*. 2001;15(4):161-167. Available at: <http://www.sciencedirect.com.ezproxy.bu.edu/science/article/B6WKK-45WHVB7-H/2/48eb47a221900c1b6b5a63a201f7bd64>. Accessed January 6, 2011.
46. Lipson M. What do you say to a child with AIDS? *The Hastings Center Report*. 1993;23(2):6-12. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/8463092>. Accessed March 1, 2011.

47. NACO. Antiretroviral Therapy Guidelines for HIV-Infected Adults and Adolescents Including Post-exposure Prophylaxis. 2007.

48. NACO. PAEDIATRIC ART COUNSELLING TRAINING MODULES FACILITATORS ' GUIDE. 2007;

49. NACO. *PAEDIATRIC ART COUNSELLING TRAINING MODULES PARTICIPANTS ' MANUAL*. 2007.

50. Anon. Psychosocial Care for HIV Infected Children and Adolescents: A Training Manual. 2009.

51. WHO. *Guideline on HIV disclosure counselling for children of ages up to 12 years*. 2011. Available at: http://whqlibdoc.who.int/publications/2011/9789241502863_eng.pdf.

52. Waugh S. Parental views on disclosure of diagnosis to their HIV-positive children. *AIDS Care*. 2003;15(2):169-176. Available at: <http://www.ncbi.nlm.nih.gov.ezproxy.bu.edu/pubmed/12856338>. Accessed March 1, 2011.

APPENDICES

Appendix 1: Interview Guide for Disclosure Process

As you are directly involved with the children served by this organization, and responsible for working with them and their families/caregivers to inform them of their HIV status, we want to learn, in some detail, how you do your work. We are going to ask you a series of questions about the disclosure process.

For this interview, we define the disclosure process as talking with children about their own HIV status or the HIV status of a family member.

Please answer each question by telling us what typically happens in your work. We are more interested in your description of actual practice in working with the children and others more than we are interested in how you were trained to do disclosure or how you think disclosure should occur. When possible, please provide examples from specific cases of your work with the children to help us understand your answer to the questions.

No personal or confidential information will be solicited about you and you will not be identified in the report. You can choose to not answer any question and if you choose to answer a question “off the record,” notes will not be taken and that information will not be included in the final report, and you can stop the interview if you feel the need. The interview should last for approximately one to two hours and the interview will be recorded.

We need to abide by principles of privacy and confidentiality when discussing particular cases. No reference to the name of any beneficiary should be made during this interview and no other identifying characteristics should be discussed. You may refer to your case notes to refresh your mind on the case, but may not show these notes to the interviewer at any time. Please affirm now that you understand this requirement before we begin our discussion. (All involved staff will be asked to affirm to maintain their understanding and compliance with this principle of maintaining privacy and confidentiality).

Date	
Organization	
Interviewer initials	
Years in the organization	
Position in the organization	
Years in this role	
Number of families served	
Number of full disclosures completed	
Number of partial disclosures completed	

1. Experience with Disclosure

To start with, we are interested in understanding how children receive information about HIV and about their own status.

1.1	Where do children you work with receive their first source of information on HIV? <i>[Probe for how they get this information (family, school, friends, NGO, ART clinic), what kind of information they get, how this changes with age, important life events]</i>
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1.2	<p>In your experience, what are the different ways a child finds out about their HIV status?</p> <p><i>[Probe for whether starting disclosure is planned or not, whether a decision to disclose is made (if so, who decides and why it was made), who initiates the discussion (parents/caregivers/friends/siblings)]</i></p> <p><i>[Probe for when and why a child starts asking questions]</i></p> <p><i>[Probe for what other factors cause the child’s status to be disclosed/revealed to them (particular event or milestone, starting ART, CD4 count, and loss of parent).]</i></p>
1.3	<p>When a family enters your program, how do you determine how much a child knows about their HIV status?</p> <p><i>[Probe for how and where information is collected, what questions are asked, who in the family is spoken to, how it is documented]</i></p>
1.4	<p>If a child has not been tested before entry into your program (both residential and non-residential), please describe the testing process and your involvement in it. What happens if the child tests negative?</p> <p><i>[Probe for how the decision is made to have the test (medical advice, based on parents status, initiated by the child, gender or age difference) and who makes it, how the test is scheduled, experience of pre-test counseling, and where is it done, who accompanies the child, how the test is explained to the child (including whether the child is aware it is an HIV test)]</i></p> <p><i>[Probe for the barriers to testing and concerns voiced by parents/caregivers/children]</i></p> <p><i>[Probe for who a child’s test results are communicated to (parent/caregiver, child with parent, child alone) and where, post-test counseling, what the child is told, how much the child knows and understands, how the organization finds out about the results, effects of the results on parent/caregiver/child]</i></p>
1.5	<p>If a child does not know their HIV status, what explanations are provided for:</p> <ul style="list-style-type: none"> - CD4 check ups - Starting ART - Frequency of health problems - Additional attention and visits from health workers - Differences in the amount of food/nutrition one child receives <p><i>[Probe for if the child’s questions increase, how long not knowing status lasts, what happens]</i></p>
1.6	<p>Do you think children have a “right” to know their HIV status? Why?</p> <p><i>[Probe for whether parents / caregivers have a right to deny disclosure to their children and if the age of the child affects this right]</i></p>
1.7	<p>Before we move onto the next section, is there anything else that you would like to add about your experience with disclosure and how children receive information about HIV and their status?</p>
<p>2. Role of parent/caregiver and siblings in disclosure</p> <p><i>Before we discuss how you disclose to a child, we wanted to talk about the role parents/caregivers, siblings and other household members play in the discussion of a child’s HIV status with the child as well as how you support them.</i></p>	

2.1	<p>What makes parents/caregivers more or less likely to discuss a child's HIV status with the child?</p> <p><i>[Probe for how the family/household situation affects the disclosure process? Consider:</i></p> <ul style="list-style-type: none"> - Orphan status (maternal, paternal, double or both parent's alive] - Age/Gender - Pre-existing family dynamics & support of extended family <p><i>[Probe for how the HIV status of other household members effect a family's desire to disclose and the disclosure process. Explore scenarios where parents were positive/negative, where there were several siblings, where there was an older sibling who was positive],</i></p> <p><i>[Probe for differences in knowledge of HIV in the family and effect of this on disclosure]</i></p>
2.2	<p>What approach is taken by parents/caregivers when they disclose a child's HIV status to the child?</p> <p><i>[Probe for how parents discuss a child's HIV status with the child and strategies used by parents, who discloses and differences in approach between mother/father/caregiver]</i></p>
2.3	<p>If a parent/caregiver is HIV positive, how do they disclose their own HIV status to children?</p> <p><i>[Probe for how parents disclose to their child about their own status and what they say, barriers to disclosure, advantages, who else discloses a parent's status to the child (sibling, NGO, household member), whether this is done at the same time as disclosing the child's status (if relevant), responses of parent/caregiver and child, effect on behavior of child at home and in the community]</i></p>
2.4	<p>How do you discuss disclosure with parents/caregivers and what support do you provide?</p> <p><i>[Probe for how discussions take place with parents about disclosure, who initiates these discussions, support provided before and during the process, questions asked and concerns voiced by parents/caregivers about disclosure of a child's status, difference between parent or caregiver]</i></p> <p><i>[Probe for response/reaction when:</i></p> <ul style="list-style-type: none"> - Family didn't want to talk - There were concerns about child revealing information in the community - You felt the child was too young and not ready to receive this information - You thought the child needed to know and others do not agree]
2.5	<p>What role do siblings play in disclosure to a child? What role do friends (at residential care facility) play in disclosure to a child?</p>
2.6	<p><i>Is there anything else that you would like to add about the role of the parent/caregiver/sibling/etc. in disclosure before we move to the next portion of the interview?</i></p>
<p>3. When the NGO practices disclosure</p> <p><i>We have talked about how, in your experience, parents/caregivers and siblings approach disclosure of a child's status to the child and the support you provide them. Now we will talk about your involvement in the disclosure process directly with a child and how this changes as a child grows and develops.</i></p>	
3.1	<p>How do you develop a trusting relationship with children and families and what effect does this have on the disclosure</p>

	process?
3.2	<p>When you have to disclose a child's HIV status to the child, please describe your approach and your involvement in the disclosure process as well as how this changes with the developmental stage of the child. Use different scenarios/conversations to answer the question.</p> <p><i>[Probe for consent process with parents, when disclosure takes place, how far the first conversation goes, where it takes place]</i></p> <p><i>[Probe for how the disclosure narrative changes with age and when the word HIV is used, how the conversation continues]</i></p> <p><i>[Probe for strategies used like art, stories, group discussions, role plays, others; what happens when use these strategies]</i></p> <p><i>[Probe for how young is the youngest child you have had disclosure conversation with, what the typical age of children is when disclosure happens, whether the opinions parents have differ or not]</i></p>
3.3	<p>When you discuss disclosure with a child, how do you handle the issue of disclosure of parent's status or a sibling's status?</p>
3.4	<p>How does a child's gender affect the disclosure process?</p> <p><i>[Probe for whether it is easier with girls or boys, whether girls or boys can be told earlier, whether a different approach is taken depending on gender (especially during adolescence), the opinions parents typically have]</i></p>
3.5	<p>How does the child's, parent's or extended family's psychological state affect the disclosure process?</p> <p><i>[Probe for how a child's emotional state affects the decision to disclose, how this is understood, the opinions parents typically have, probe for children who don't have links to the family]</i></p>
3.6	<p>How do puberty and sexual maturity affect the disclosure process?</p> <p><i>[Probe for early adolescence and late adolescence how relationships, safe sex, marriage are discussed, effect of gender, opinions parents typically have]</i></p>
3.7	<p>Please describe the different reactions once a child's status has been shared with the child and the family? Consider reactions of:</p> <ul style="list-style-type: none"> - The child - Siblings - Other household members - Friends at the residential care facility (home) <p><i>[Probe: Behavioral changes related to this disclosure, change in relationships, questions asked by the child and other family members, changes in adherence (if relevant), changes in care and nutrition, changes in social relationships, worries or concerns voiced, financial concerns, high risk behavior, violence]</i></p> <p><i>[Probe for positive/negative outcomes seen over time]</i></p>
3.8	<p>When do you consider disclosure to be complete?</p> <p><i>[Probe for why, how the conversation continues, who continues the conversation with the child/caregiver/other family members]</i></p>

3.9	Before we move on to the next section, is there anything else that you would like to add regarding how the organization practices disclosure?

4. Situations faced in counseling and training provided	
<i>We are interested in hearing your experience when you face certain situations and in learning more about how you support children and families. Please use specific examples from your experiences. If you have not had this experience, tell us and we will move to the next scenario</i>	
4.1	<p>Could you describe how children disclose their own status to others (like parents, siblings friends or a girl/boyfriend)? What support do you provide?</p> <p><i>[Probe for support provided and the effect this disclosure has on the child]</i></p> <p><i>[Probe for how children disclose to their siblings, examples including examples of a child disclosing a parent's status, their own status and the sibling's status, events/circumstances leading to this, effect of this on children, effect on sibling relationships]</i></p>
4.2	Could you describe how the NGO discloses to school (teachers) /doctor/other service providers?
4.2	<p>What information and support do you provide families and children on pre-ART or ART medications?</p> <p><i>[Probe for information given on adherence, how it is discussed, whether adherence changes with disclosure]</i></p>
4.3	<p>What type of counseling and support do you provide when:</p> <p>a) child and/or parent is emotionally distraught or depressed b) a parent is very ill or dying? c) not adopted (due to status)</p> <p><i>[Probe for frequency of interaction with family, support provided to child, referrals, hospital visits, support with funeral arrangements, financial support, legal support (death certificate, will, alternative caregivers and arrangements, foster care, relocation of children and changes in residence)]</i></p>
4.4	<p>How do you ensure privacy and confidentiality?</p> <p><i>[Probe for meaning of confidentiality, confidentiality policy and process in organization, when and how this is explained to beneficiaries, process for home visits, storage of data on beneficiaries]</i></p>
4.5	<p>What do you find challenging about disclosure conversations?</p> <p><i>[Probe for parts of the conversation that are easy, what you do if you are not feeling comfortable or equipped to disclose a child's HIV status to them, does it differ by age, gender, Male social worker to male child and female social worker to female child]</i></p>

4.6	<p>Describe how you learned to discuss disclosure.</p> <p><i>[Probe for whether any formal training was provided and content, who organized this training, why the organization attended, whether there was follow up training, has the training changed overtime/how, what additional training would be useful]</i></p> <p><i>[Probe for number of years and cases, first experience, how experience has changed, whether training had been provided before work on disclosure started]</i></p> <p><i>[Probe for whether guidelines exist in the NGO and if they are used]</i></p> <p><i>[How has your experience and/or training helped you to handle disclosure issues with the families and children that you care for]</i></p>
4.7	<p>Before we move onto the next section, is there anything that you would like to add in terms of counseling and training?</p>
<p>5. Local context and policy recommendations</p> <p><i>Finally, I would like to understand more about the context in which you are working and also discuss ideas for policy level changes and improvements that you have.</i></p>	
5.1	<p>Based on your experiences, could you describe good practices for discussing a child's HIV/AIDS status and practices which disappointed you? Please think about other NGOs, government hospital and facilities, doctors.</p> <p><i>[Probe for whether these were child friendly, and for practices used by government institutions, organisations, and ICTCs]</i></p>
5.2	<p>In your State, what support and resources do doctors, counsellors and social workers receive to do disclosure? Is this adequate?</p> <p><i>[Probe for differences in resources (infrastructure, financial, training) between government and NGOs, whether guidelines exist, suggestions for improvement]</i></p>
5.3	<p>Are you aware of any laws relevant to the disclosure of HIV status? If so, what are they?</p>
5.4	<p>What recommendations would you provide to your NGO or the State or National AIDS Control Societies on how to deal with disclosure issues?</p> <p><i>[Probe for whether guidelines should exist and changes to these, suggestions for legal changes, where disclosure should be done, the role of government hospitals, NGOs]</i></p> <p><i>[Give a situation: If head of NACO what changes would you make to address disclosure issues?]</i></p>

Thank you very much for your time. Is there anything else you would like to add that we did not cover? Do you have any questions?