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Lessons Learned from Social Support Services for Families and Children Living with HIV: Practices Outside of Ukraine

The review of international experience

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List of Abbreviations

AIA  Abandoned Infants Assistance Act (U.S.)
AIDS  Acquired Immunodeficiency Syndrome
CDC  Centers for Disease Control
CIWI  Coordinated Intervention for Women and Infants
CPAFCY  Centers for social services to families, children, and youth
CPR  Cardiopulmonary resuscitation
DCF  Department of Children and Families (Yale University)
DfES  Department for Education and Skills (UK)
DFID  Department for International Development (UK)
DHHS  Department of Health and Human Services (U.S.)
DMC  Developmental Medicine Center (Harvard University)
HHS  Health and Human Services
HIPAA  Health Insurance Portability and Accountability Act (U.S.)
HIV  Human immunodeficiency virus
ICD  Institute for Child Development (Romania)
IMCI  Integrated Management of Childhood Illnesses
MDGs  Millennium Development Goals
MDR-TB  Multiple drug resistant tuberculosis
MFYS  Ministry of Family, Youth and Sport of Ukraine
MOH  Ministry of Health of Ukraine
NCCD  National Council on Crime and Delinquency
NGO  Non-governmental organization
PHL  Public health law
PLHIV  People living with HIV disease
PMTCT  Prevention of mother-to-child transmission
QAP  Quality Assurance Project
TB  Tuberculosis
UK  United Kingdom
UN  United Nations
UNGASS  United Nations General Assembly Special Session
UNICEF  United Nations’ Children’s Fund
U.S.  United States
USAID  U.S. Agency for International Development
VCT  Voluntary counseling and testing
WHO  World Health Organization
XDR-TB  Extensively drug resistant tuberculosis
I. Executive Summary

This paper provides highlights of lessons gleaned from review of a selection of current social support practices for families and children living with HIV. The selected practices are drawn primarily from developed country settings with abundant resources and well-organized public social service delivery systems.

These lessons are meant to inform the Government of the Ukraine as it embarks on policy and programmatic reform in order to build a more unified, coordinated, comprehensive national approach that is responsive to the varied needs of families and children living with HIV. This document is not meant to be prescriptive but rather to present lessons learned from selected family-based and child care programs, recognizing that what is appropriate for one country in terms of caring for HIV-affected parents and children will differ from another, based on different contexts, resources, and different cultural norms regarding childhood, parenting, family care, childcare, and child protection. The intent is to provide guidance to assist the Government of Ukraine in adopting standards of social services delivery for: a) HIV-positive children, HIV parent(s), and their families, and b) other children affected by HIV without families who may be in need of foster care, adoption, or other care arrangements.

Highlights of lessons learned include the following:

- International child-rights principles and consensus among global experts proffer that it is in the “best interest” of the child to provide family-centered and family-based programming for children affected and/or infected with HIV, if at all possible. Long-term care that affords the security of family or family-like relationships, clear lines of responsibility, full access to a wide range of support services (including financial support), and legal permanence is preferable.

- Programming for social services is predicated on a holistic approach addressing the needs of the child or youth, parents or guardians, and other family members interacting and mutually supporting one another within a “family system.” Every effort should be made to support a family to stay intact; to support at risk mothers, to prevent HIV infection and provide long-term antiretroviral, substance abuse, TB, and other treatment and prophylaxis for adults/parents living with HIV (in order to prevent orphans); and to economically and emotionally stabilize families with members who may be incarcerated, in treatment, rehabilitation, or enduring other separations that can negatively effect children, particularly when combined with the social isolation and stigma that often accompanies HIV. Many national child protection acts are being amended to stipulate that institutional care of children should be provided only as a last resort.

It is widely acknowledged that it is a significant institutional challenge to create a linked, multisectoral and multilevel system of social and other services in order to meet the different age- and developmental-specific needs of children and their families variously affected by HIV. Most effective integrated systems approaches maximize partnerships between public service delivery and non-government, particularly community-based organizations, and between formal systems of care and support and informal systems, such as peer support groups among people living with HIV. Interlaced within generalized formal and informal, government and non-government services are approaches tailored to meet the specific needs of children and families living with the medical and social impacts of HIV and concurrent disabilities. National child- and youth-focused strategies include specific standards to assure access to appropriate services for these children and their families.
In a number of countries with integrated systems for care and support of children, social service departments and health departments work closely together to systematically analyze, understand, and track progress of children and young people within their families and the wider context in which they live. Social services play a pivotal role in providing counseling; addressing stigma associated with HIV; imprisonment; disability and other conditions; supporting adherence to treatment; and referring children and families in need of prophylactic or comprehensive treatment.

The concepts of providing both a high quality “comprehensive package of services” and an integrated, well-coordinated “continuum of care” suggest the need to institute flexible approaches that allow for the changing and multiple needs of each individual child to be met. These approaches are uniformly based on the following four practices:

1. **ongoing, comprehensive needs analysis and regular progress monitoring** – of children/young people and adults and other family members living with HIV;
2. **an interdisciplinary approach with teams of educators, social workers, and health workers providing focused clinical and psychosocial “shared care”** to the same child and/or family client;
3. **case management practices and standards that define minimum agency service requirements and that ensure uniformity and continuity of care** as clients’ circumstances change over time and stage of HIV illness; and
4. **meaningful participation of children throughout the care and support approach.** Children and young people are increasingly directly involved in decisions, policies, and improvements in service delivery that affect their own care and lives.

A number of countries with previously large numbers of individual children living in residential care facilities are undergoing policy and programmatic shifts to ensure that children are either returned to their families or receive care and support within family-based care models. **Deinstitutionalization of children is widely being undertaken in order to reduce discrimination linked with institutionalization, to promote optimal growth and development, and to provide the most cost-effective care, support, and nurturance in family-like settings.**

Disclosure of HIV status is an individual (child or parent) and family concern and decision that pivots on a combination of privacy issues, health care and social service needs, and the negative effects of stigma. One of the conceptual pillars for ensuring child protection while providing social services support is **broad enforcement of public health laws that uphold confidentiality and informed consent procedures for disclosure of HIV status or HIV-related information among health insurance plans, health care information clearinghouses, and any health care or social services provider who transmits health information in written or electronic form.** Another protective pillar is individual authorization through **informed, written consent.** A third protective pillar is provided through **local child centers and hubs that can serve as networks to implement national child rights protection laws in a manner that is responsive to each local condition,** reaching especially poor, marginalized, and other vulnerable children such as children in conflict with the law and street children; and children and their families affected by HIV, substance use, tuberculosis, and other intersecting issues.

**Effectively and efficiently coordinating and managing multiple services reaching individual children and families living with HIV require the best use of (usually limited) resources and the application of evidence-based interventions, services, and support.** Key elements to address complex management demands include:

- Policies that provide equal opportunity and access to child welfare and child protection services by all, including children and families living with HIV.
• Well trained multidisciplinary teams providing services by following coordinated care plans that attain high quality standards through continuous assessment, tracking, and quality improvement programs. This requires continual performance- and ethics- based staff training; adjustment of appropriate staff ratios to case loads; a proactive system for ensuring confidentiality; and adequate, supportive, and corrective supervision.
• Well designed communication and referral networks, based on multiple and reciprocal service agreements that include HIV service organizations and support groups of people living with HIV.
• A system of monitoring that incorporates international standards and indicators.

It is important to note that this paper is developed for the Ukraine Ministry of Family, Youth, and Sport (MFYS), which specifically asked USAID|Health Policy Initiative, Task Order 1 in Ukraine to do provide examples of social service practices in other countries outside of Ukraine. The identification of social support practices for children and families affected by HIV is not an end in and of itself. Rather, these practices, principles, and “lessons learned” are meant to be used interactively with a group of major child-focused stakeholders to improve the national systematic adoption and adaptation of practices in the context of the Ukraine. Toward that end, a Roundtable on the Exchange of Experience and Discussion of Practices of Social Service Provision to HIV-positive Children, Children Affected by HIV, and Their HIV-positive Families was organized as a way to participatorily review, digest, and begin to organize application of these practices more comprehensively and systematically. Many of the models, approaches, and underlying standards are also useful for development of adjunct monitoring and evaluation and quality assurance systems to ensure widespread adoption during scaled up implementation of the National Plans of Action, once finalized in the months to come.

On July 19, 2007, in Kyiv, Ukraine a Roundtable on the “Exchange of Experience and Discussion of Practices of Social Service Provision to HIV-positive Children, Children Affected by HIV, and Their HIV-positive Families” was held at the Ministry of Family, Youth, and Sport (MFYS). USAID | Health Policy Initiative, Task Order 1 in Ukraine Futures presented a synthesis of lessons from review of literature and case studies from countries outside of Ukraine and international practices of social service provision to HIV-positive children and their families.

Presided over by a panel that included representatives from the Ukrainian Ministry of Family, Youth, and Sport (MFYS), Ministry of Internal Affairs, State Penitentiary Department, Ministry of Education, USAID|Ukraine Mission, USAID|Health Policy Initiative, and the All-Ukrainian Network of People Living with HIV, the roundtable was the first occasion for in depth presentations and review among 39 child service representatives from multiple Government of Ukraine ministries, state departments, and non-government organizations. Participants realized, some for the first time, that there is a common, child-focused agenda evolving in the Ukraine.

This event provided a platform of initial discussions and partnerships that can further enhance coordination of care for children and families living with HIV and encourage adaptation and scale up of best practices during implementation of the National Plan of Actions carry out the UN Convent on Children Rights in Ukraine through 2016. The National Plan of Actions was submitted to Verhovna Rada for approval and was approved as a draft at the first reading on February 8, 2007.

Current social support responses to children and families affected by HIV in the Ukraine are mostly pilot or small scale programs. As noted during the Roundtable, many of these programs include one or more internationally-recognized practices without necessarily incorporating these practices into more comprehensive social service delivery to HIV-affected children. Also, current consensus has not yet been
established to constitute criteria for good or best social service practices for children/families with HIV in the Ukrainian context. A determination of criteria is an essential next step in order to scale up promising program efforts and to develop a systematic approach for implementation of the National Plans of Action. In addition, some of the issues that surfaced during Roundtable discussions for possible further exploration and action include:

- Lack of a systematically planned and government-wide endorsed effort to protect confidentiality, build tolerant social norms, and address the negative effects of stigma and discrimination on children and families living with HIV;
- No clear, consolidated database on the current status and location of orphans with HIV for coordination between the MOH, MFYS, and other ministries;
- Need to reform institutional care (including boarding schools) so that children and youth live in more family-like environments, at the same time that efforts are improved to locate relatives of these children;
- The importance of improving the system for recruiting quality foster families, including those willing to integrate children/youth living with HIV into their families; and the need to streamline the bureaucratic barriers to placing children in foster care (including eliminating taxes on pensions of children living with HIV);
- The growing number of HIV-positive mothers (reportedly increasing by 20% each year in the Ukraine) and the need to address the vulnerability of their newborns (as many as 20% of their children are abandoned); there is a related need for counseling and training pregnant women in order to better care for their newborns and children;
- Need for improved psychosocial support of children living with HIV, particularly during adolescence when a youth’s HIV status is no longer concealed; this includes the need for improved recreational opportunities;
- A gap in providing sufficient economic support to biologic and foster families with children living with HIV;
- Need for a situational analysis and concerted strategy to help reunify street children and “social orphans” with families (estimated that up to 30% of homeless children could be HIV positive);
- Need for an “early identification” system for families and children in crisis and improved training of multidisciplinary teams (perhaps a public training institute) to provide social support for immediate and long-term care of minors;
- Lack of sufficient community-based linkages between AIDS Centers, day care centers and providers, and social services for children and families living with HIV; and the need to increase access to and utilization of existing social support networks;
- Need to study all child “loss to follow-up” cases within the current social support provision system (including children/youth who are “runaways” from institutions) in order to improve services and support (it is estimated that 20-25% of institutionalized children have escaped at least once, most often due to cruelty);
- Need to improve provision of antiretrovirals and psychosocial support to HIV-positive juveniles detained in jails;
- Need to provide technical support for local government and regional planning in order to improve the number and professional reputation/quality of social workers;
- Need to intervene with and support families that are dysfunctional, experiencing substance abuse, violence, poor parenting, and other major problems that result in poor quality child care; and
- Future social service strategies need to prioritize HIV prevention among youth, including youth currently abusing drugs and alcohol, PMTCT, and prevention of orphans.
II. Introduction and Background

Purpose

In April 2006 the Ministry of Family, Youth and Sport (MFYS) and the Ministry of Health (MOH) of the Ukraine issued a joint decree (no. 1209/228) to approve procedures for interface of regional, town, and district centers for social services to HIV-positive families, children, and youth (CPAFCY) and medical institutions providing medical care and social services to children and youth. The approach incorporates principles of youth-friendly services recommended by WHO and UNICEF and is built on a wide array of provisions of the Ukrainian constitution and laws providing medical, preventative, and psychological assistance to children and youth. Ukrainian law defines two ways of providing social services, i.e., via financial or material welfare assistance and via an array of public social services: social and personal assistance, psychological services, social and pedagogic services, social and medical services, social and economic services, legal services, employment services, professional rehabilitation services, and information services (Article 5, law of the Ukraine “on social services”).

As the MFYS and MOH begin to operationalize this joint decree, there is an opportunity to consider, learn from, and systematically adopt youth-friendly and family-centered models/approaches and standards of social service delivery being implemented primarily by countries with well-developed and tested systems for providing social assistance. This review of a selection of pertinent literature has been undertaken in order to support the Ministry of Family, Youth and Sports in their efforts to improve family-centered child welfare in the Ukraine. The paper highlights current practices in provision of social services and social sector reform in order to inform the MFYS and other government partners, such as the MOH, in better carrying out and improving a number of legislative orders related particularly to the care and support of HIV-positive families (i.e., families in which adult(s) and/or children are living with HIV) as well as individual children and their non-familial caretakers. The paper complements the soon to be completed USAID | Health Policy Initiative, Task Order 1, Ukraine overview of the current legal and regulatory social support framework for five groups of children and their families in Ukraine: (1) HIV-positive children; (2) adopted children; (3) children in prisons; (4) children in socially unprotected and poor families; and (5) orphans.

The overall goal of this review of selected current social support practices is to inform a more unified, coordinated, comprehensive national strategy to address the needs of HIV-positive families and their children in a way that also builds the capacity of major government and non-government stakeholders. The purposes are two-fold:

- To compile lessons learned and practical considerations from current social support practices for families and children living with HIV, especially those from countries with well-organized public social service systems.
- To provide guidance to assist Ukraine in adopting standards of social services delivery for: a) HIV-positive children, HIV parent(s), and their families, and b) other children affected by HIV without families who may be in need of foster care, adoption, or other care arrangements.

This document is not meant to be prescriptive but rather to present lessons learned from selected child care and family-based programs, recognizing that what is appropriate for one country in terms of the “proper” way of caring for HIV-affected parents and children will differ from another, based on different contexts, resources, and different cultural norms about the nature of childhood, childcare, and child protection.
Global Context –Importance of Social Support to Families with HIV

International consensus has crystallized around a platform for action to increase coverage of essential services, care, support and treatment to orphans and other vulnerable children, including those affected by HIV and made vulnerable by a multitude of other interacting factors including poverty, violence, and concomitant stigma. It is widely recognized that governments are responsible for strengthening social security and support systems with improved coverage/reach of those poorest and most vulnerable HIV-affected families and children. Recognizing that the exclusion of children and youth from services and support, protection, and opportunities that are their rights is unacceptable, a number of international agreements have been developed to steer global response to families and children affected by HIV.

Ukraine was an active member in the 2001 UN General Assembly Special Session on HIV/AIDS (UNGASS). Ukraine signed on to the UNGASS Declaration of Commitment on HIV/AIDS, June 2001, which includes three specific goals directed at meeting the needs of orphans and vulnerable children:

1. “…Implement national policies and strategies to build and strengthen governmental, family, and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV…”
2. “Ensure non-discrimination and full and equal enjoyment of all human rights through the promotion of an active and visible policy of de-stigmatization of children orphaned and made vulnerable by HIV…”
3. “Urge the international community, particularly donor countries, civil society, as well as the private sector, to complement effectively national programs to support programs for orphans or children made vulnerable by HIV…”

A multi-tiered process of global and regional consultations among development practitioners, and representatives from a diverse array of government, non-government, faith-based, private sector, academic, and civil society organizations resulted in the Framework for Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS (July 2004). The Framework lays out a common agenda built on five key strategies:

1. Strengthen the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial, and other support.
3. Ensure access for orphans and vulnerable children to essential services, including education, health care, birth registration, and others.
4. Ensure that governments protect the most vulnerable children through improved policy and legislation and by channeling resources to families and communities.
5. Raise awareness at all levels through advocacy and social mobilization to create a supportive environment for children and families affected by HIV/AIDS.

Social security has been a key tool to address inequality and exclusion by assuring free access to health, education, and other services for families living in poverty, and providing a package of social assistance payments to ensure a minimum standard of living. Many government social services include systems of social assistance payments to families eligible via economic income criteria, provided in order to specifically pay for health care, education, and welfare of families living below the poverty line. Social assistance payments are usually in the form of cash transfers. They are not necessarily child-targeted, but
rather reduce families’ vulnerability to HIV without further stigmatizing those families living with HIV. They include:

- Social pensions
- Child benefits (e.g., “Child Support Grant”)
- Conditional cash transfers
- Disability allowances
- Unemployment benefits

An international advocacy summit held in Brussels in early 2007 reinforced the importance of ensuring sufficient financial support to families and communities to enable protection of HIV-affected children without stigma. The summit is calling for specific funds to address child protection and social support, including wider funding of cash transfers to support families in need.

Clearly, international commitments to HIV-positive families, including HIV-positive parent(s) and their children, are increasingly cognizant of the government’s key role in providing a wide variety of family-focused social support services. This requires increased government resources to build the capacity, reach, and system of a strengthening social services ministry that works closely with HIV-positive families, communities, and non-government partners.

A number of countries have recognized the transformational nature of social investment in their citizens and responded with commitments to increase protection for children orphaned and affected by HIV, including building and/or strengthening social security systems to better protect children and their families. For example, the United Kingdom’s Department for International Development (DFID) issued a white paper in 2006 outlining significantly increasing spending on social protection in at least 10 countries by 2009.
III. Lessons Learned from Current Social Support Practices

Package of Care and Support Services

As a result of the HIV epidemic and its link to substance abuse, tuberculosis (TB), poverty, and other major vulnerabilities, many countries are facing demands of caring for a particularly needy group of families and children affected concurrently by multiple debilitating conditions. The impact of a parent or other family member living with HIV affects the functioning of entire family, and children whose parent(s) may be chronically ill or are dying are particularly impacted. The challenge is to address the myriad of needs across the entire spectrum of HIV-positive families – ranging from parent(s), children and other family members struggling with HIV related shame, fear, stigma and discrimination; to ill health, lack of appropriate medical care, side effects from medication; to grieving when a parent or child is dying; to healthy adolescents in need of counseling and economic support; to planning for the child’s future in case the parent(s) dies such as custody, placement, and bereavement; to families coping with divorce, migration or expatriation, drug use (including alcoholism), TB, mental illness, disability, domestic violence, imprisonment, housing problems, and/or the risk of homelessness.

Some of the literature uses the term a “package of care and support” (Tolfree, 2006). The premise is that care options should be biased towards helping a child remain safely in a family or extended family which is meeting that child’s needs and rights. While residential care is the “last resort” option, it is clear that family-centered support, substitute care, and care and support for caretakers/parent(s) may be complementary when the overall goal is to utilize short-term care outside the family to achieve particular objectives that will ultimately improve care of the child within the family environment.

Because there is no single solution that will fit all family situations and yet be in the “best interests” of the evolving child, it is imperative that parents/guardians and children living with HIV are able to work directly and collaboratively with government and non-government direct service and support providers in order to identify and prioritize their needs and access services that are across diverse agencies and sectors of development. The challenge is creating a linked system of services and a method of referral among those services that will provide a multisectoral response to the different needs of families and children variously affected by HIV.

The concept of a “package” or “continuum of care” is not a unilinear approach but rather one that allows for the changing needs of a child to be met, based on comprehensive analysis of needs and regular monitoring of progress. A regular review schedule involving the child, parents or caretakers, and service and support providers is critical to providing a continuous, flexible, responsive care environment that respects the active involvement of children and their parents or guardians. A basic five tier continuum of care and services is prescribed by U.S. family-centered practice in child welfare (National Child Welfare Resource Center for Family-Centered Practice, 2000), to which two additional service areas have been added, informed by Canadian child care advocates (The Teresa Group, 2001 and 2007):

1) Prevention – education and developmental services useful for children and families; approaches that diminish the need for children to be separated from families (i.e., in the case of parental illness, abandonment, poverty). In the context of HIV, the concept of prevention extends to:
   a) Prevention of orphanhood by providing HIV prevention education and risk reduction support, including parenting skills and support for families to stay together.
   b) Prevention of pediatric HIV via prevention of mother-to-child transmission
c) Prevention of family separation to reduce the risk of children needing care outside of the family. Some basic community development services may have a preventive effect, such as improved access to education, economic support and income-generating schemes, etc. (Tolfree, 2006).

2) Supportive, problem-solving, and crisis intervention assistance – for children and families coping with normal processes of growth and development as well as crises which can be common occurrences for HIV-positive families; types of support can include day care, emergency crisis care, support for hospice and palliative care, and other appropriate substitute care for a whole range of emotional, social, educational, and spiritual needs.

3) Rehabilitation – protection for children and assistance to seriously disorganized and dysfunctional families, including temporary child protective services in order to restore family functioning and to prevent family breakup.

4) Out-of-home care and support/care for caretakers/parent(s) – assistance for children at risk for neglect or abuse within their families, including placement, supervision, and family rehabilitation and reunification. As a last resort, this includes group care and institutional care. Support/care for caretakers/parent(s) includes short-term or temporary care (a few hours or weeks) of the sick or disabled in order to provide relief (“respite”) to the parent or caregiver, who is usually a family member.

5) Future care planning for children – reunification plans; plans of support and temporary shared custody for children with HIV who are chronically ill and/or who are living with chronically ill parents; plans for adoption or permanent guardianship; and plans for the future care of children for families with HIV that may not have extended families. Follow-up and emancipation services are included. The process of future care planning should be time-limited to provide the child with continuity of relationships.

6) Parenting support – skills building training, counseling, information about family planning options for parents living with HIV, and information about community resources. Parents may need help understanding their children’s behaviors, which ones are normal, and which ones may be due to HIV (The Teresa Group, 2007). Parents with HIV often feel less isolated when learning from each other, including sharing resources such as day care or child care to assist when they are working.

7) Coping and bereavement support, especially for children – It is imperative that workers learn the skills for maintaining the mental health and well being of children who are coping with the effects of HIV within their family and/or who survive the loss of a parent due to HIV. Bereaved children deal with a profound sense of loss which left untreated often results in emotional and psychological distress. The secrecy that may surround a family member's cause of death can result in further heightened levels of anxiety, anger and sadness (Teresa Group, 2001). A recent study points out that children who are bereaved but are unaware of the true cause of death (non-disclosed), are fearful and often do not feel hopeful for the future (Kindy-McPherson, 2004). Social workers and other practitioners need to develop specialized skills in order to facilitate the developmental stages of grief and loss as they relate to children.

"Sometimes it's scary to think about the future" (Parents with HIV)

"I often forget that people with HIV/AIDS can be parents too"
The Childhood Bereavement Network, a national and multi-professional association of organizations and individuals working with bereaved children in the UK, has produced a number of good practice guides for those working with bereaved children and young people, their families, and other caregivers. The following guidelines for practitioners, service providers, and others working with bereaved children cover the areas of safety, practice context, quality, accountability and equality.

There are a range of options available to practitioners, policymakers, and others with responsibilities for the care and support of HIV-positive parent(s), their children and families affected by HIV. The lessons, case studies, and practical implications in the next section of this paper are drawn from a wide variety of practices that may be relevant or appropriate in very different family, social, cultural, and other traditions.

**Confidentiality and Disclosure of HIV Status**

An individual’s HIV-related information is considered “extremely confidential.” When providing services for anyone infected or affected by HIV, confidentiality in regard to information about their illness or their current situation is paramount. Maintaining a child or adult’s confidentiality about HIV status is a matter of ethics as well as law and is both an individual privacy and public health concern when sharing HIV-related information between persons and care workers, to fulfill reporting requirements, between organizations, and between service delivery systems. In the United States, the 1996 federal act, HIPAA (Health Insurance Portability and Accountability Act) ascertains that the federal Department of Health and Human Services (HHS) has the authority to promulgate regulations containing standards with respect to the privacy of individually identifiable health information, including HIV information.

The federal standards regulate the use and disclosure of health and other information, including HIV status, among health insurance plans, health care information clearinghouses, and any health care provider who transmits health information in written or electronic form. HIPAA also requires an authorization to disclose confidential HIV related information to an authorized agency in connection with foster care or adoption of a child. All disclosures require authorization, usually in the form of an individual’s informed, written consent. These individual authorizations are voluntary and revocable (by the individual).

New York State’s regulations of confidential HIV-related information include: “No person who obtains confidential HIV related information in the course of providing any health or social service or pursuant to a release of confidential HIV related information may disclose or be compelled to disclose such information, except to . . . an authorized agency in connection with foster care or adoption of a child” (PHL § 2782(1)(h)). New York public health laws also restrict a physician’s disclosure of confidential HIV-related information to a parent or guardian of a protected individual, including a protected minor, if in the judgment of the physician. Informed written consent includes documentation that becomes part of the individual’s records. An example of the first page of an individual’s authorization for release of HIV information (in New York state) is provided in the following box (see the Annex D for the complete form):
Disclosure of HIV status is an individual (child or parent) and family concern and decision that pivots on privacy issues, health care needs, and the negative effects of stigma. It may be appropriate to disclose a child’s HIV status to medical and social service staff (including doctors, nurses, dentists, psychologists, and

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### HIPAA Compliant Authorization for Release of Medical Information

New York State Department of Health

This form authorizes release of medical information including HIV-related information. You may choose to release just your non-HIV medical information, just your HIV-related information, or both. Your information may be protected from disclosure by federal privacy law and state law. Confidential HIV-related information is any information indicating that a person has had an HIV-related test, or has HIV infection, HIV-related illness or AIDS, or any information that could indicate a person has been potentially exposed to HIV.

Under New York State Law HIV-related information can only be given to people you allow to have it by signing a written release. This information may also be released to the following health providers caring for you or your exposed child: health officials when required by law; insurers to permit payment; persons involved in foster care or adoption; official correctional, probation and parole staff; emergency or healthcare staff who are accidentally exposed to your blood, or by special court order. Under State law, anyone who illegally discloses HIV-related information may be punished by a fine of up to $5,000 and a jail term of up to one year. However, some re-disclosures of medical and/or HIV-related information are not protected under federal law. For more information about HIV confidentiality, call the New York State Department of Health HIV Confidential Hotline at 1-800-962-5065; for information regarding federal privacy protection, call the Office for Civil Rights at 1-800-368-1019.

By checking the boxes below and signing this form, medical information and/or HIV-related information can be given to the people listed on page two (or additional sheets if necessary) of the form, for the reason(s) listed. Upon your request, the facility or person disclosing your medical information must provide you with a copy of this form.

I consent to disclosure of (please check all that apply):

- My HIV-related information
- Both (non-HIV medical and HIV-related information)
- My non-HIV medical information

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**Information in the box below must be completed.**

- Name and address of facility/person disclosing HIV-related and/or medical information:

- Name of person whose information will be released:

  - Name and address of person signing this form (if other than above):

  - Relationship to person whose information will be released:

- Describe information to be released:

- Reason for release of Information:

  - Time Period During Which Release of Information is Authorized From:________ To:________

  - Disclosures cannot be revoked, once made. Additional exceptions to the right to revoke consent, if any:

- Description of the consequences, if any, of failing to consent to disclosure upon treatment, payment, enrollment or eligibility for benefits (Note: Federal privacy regulations may restrict some consequences):

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All facilities/persons listed on pages 1, 2 and 3 if used of this form may share information among and between themselves for the purpose of providing medical care and services. Please sign below to authorize.

Signature ________________________________ Date ________________

*Human Immunodeficiency Virus that causes AIDS*
social workers) who are then required to respect the individual’s and family’s privacy by keeping the HIV status information confidential. A child’s pediatrician, general practitioner, or family doctor may need to consult with the HIV specialist, especially if the child or youth are exposed to certain infections (some of which can start in the mouth and would be recognized by a dentist).

Parents face the difficult decision of how and when to disclose their HIV status to a spouse or partner and children. Learning about the HIV status of a parent can bring stress to the spousal or other family relationships, exacerbating ongoing or provoking new family dynamic patterns in the process. Keeping a secret or delaying disclosure to children can also cause problems, since children are often very perceptive in noticing that something is causing anxiety for their parents. Three primary psychosocial issues arise for most parents disclosing their HIV status to their children: concerns about their children’s well-being; concerns that children will disclose to others outside the immediate family; and maternal fear of blame when HIV has been transmitted from mother to child (Salter-Goldie et al., 2007). Immediate and ongoing counseling and support can help to balance the needs and concerns of parents and children during disclosure. Children and youth may require age and developmentally appropriate information from a number of different disciplines in order to understand and come to terms with the impact of a parent’s HIV status on their own health, family, and lives.

Parents may also elect to disclose their HIV status to close friends and family members who can be trusted to be supportive and provide practical assistance during times of high stress. Experience shows that when families think carefully about who is most appropriate to disclose to – and for what reason(s) – they are better able to develop a circle of support and care around them.

**Family Care and Support**

Programming for social services support is predicated on a holistic approach focusing on the child or youth and other family members as a system, that is, a “family system.” Even in the most competent and stable families, the diagnosis of HIV disease can reverberate as a crisis, requiring families to confront longstanding or recently surfaced issues, and can strain interdependent family processes, roles, and boundaries for communicating, managing feelings, coping, and problem solving. The impact of HIV on a family means that the family is often trying to cope while also experiencing isolation and stigmatization. Families vary in functionality and may additionally face issues of sexuality or sexual behavior, substance use, an incarcerated family member, or a chronically ill parent being cared for by a child. Under these circumstances and recognizing the family as the primary support mechanism, the needs of a child living with or affected by HIV are best met in the context of support for the entire family, including parents and other members possibly living with HIV.

According to family system theory (which was notably shaped and applied by the British anthropologist Gregory Bateson and the U.S. psychotherapist Virginia Satir), the members of a family dynamically regulate its internal environment in order to maintain stability and equilibrium. The implication for social services is that a comprehensive process of care and support focusing on both the “best interests” of the HIV-affected child and parent(s) and other family members living with HIV is most effective in serving the child and the structure and processes of the family as a whole.

**Family Intake/ Initial Assessment**

*Lesson: The development of an appropriate package of care, support, and other services needs to be based on a comprehensive analysis of children and their parents’ needs.*
Multiple processes among multiple government and non-government agencies must be focused on early identification of families with distressed economic means, poor housing, difficulties coping with the effects of HIV, relationship problems, or other issues, in order to appropriately tailor support. Ideally, initial household assessment and intake will be included during delivery of each of the following services: PMTCT, VCT, HIV Service NGOs, PLHIV networks, HIV medical clinics, hospital settings, TB clinics, drug treatment clinics and prisons.

Short-term care can be used as part of a range of protection and care services for a family facing complex problems. Recognizing that not all families are protective of their children, these include positive care options for children who require alternative living arrangements (Tolfree, 2005). One possible model, based on experiences caring for children in highest HIV prevalence countries, consists of two main phases of care, both of which depend on a high standard of care planning that involves the child, family, and other care providers as well as regular monitoring of the child and family in order to respond to circumstances that change over time:

1) Phase I begins with assessment, advice, and counseling provided through any/all of the service intake areas described above. Individual and/or family counseling support is augmented with income support, advocacy for improved housing, and daycare as necessary.

2) Phase 2 centers on short-term fostering, temporary guardianship, or short-term residential care, recognizing that the longer a child/youth is institutionalized reduces that child’s chances of reunifying with their family. This can include diversion programming for the individual child and after-care support.

It is difficult to generalize systematic responses, since services are based on a widely variable, comprehensive analysis of each individual child’s needs, rights, and best interests. Initial assessment will also vary greatly depending on the context of the child, and whether their needs are first identified by a neighbor, a family member, a social worker, or a community volunteer or other community member.

*Illustrative Case Study:* The diagram on the next page was developed by Save the Children UK; it outlines the entire assessment and intake decision-making process followed for a 12-year-old girl who was found wandering late at night, dirty, neglected, and expressing fears about returning home. It illustrates one pathway for comprehensive intake assessment of a child or youth in the context of their family’s support needs.
Model for decision-making

Start here

12-year-old girl at home

Is she in immediate need of care and protection outside of the family?

No

Provide suitable package of protection, support and monitoring

Yes

Return her home at the appropriate stage

Does the family require support?

Yes

Place with relatives, friends or neighbours

No

Support and monitor other children in the family

Can she be placed appropriately with relatives, friends or neighbours?

Yes

Place in foster care

No

Provide alternative permanent care such as long-term fostering or adoption

Is there scope to work towards her safe return to the family?

No

Out-of-home placements (apart from adoption) require regular participatory reviews.

Note: Every step requires a detailed assessment and decision involving the child and other stakeholders.
**Practical Implications:** Standards of initial intake/assessment for public agencies providing HIV and other services include those listed in the following box:

<table>
<thead>
<tr>
<th>Initial Intake/Assessment Standards</th>
</tr>
</thead>
<tbody>
<tr>
<td>• review of client rights and responsibilities, including describing the program and explaining the services and what the client can expect if enrolled;</td>
</tr>
<tr>
<td>• overview of the agency’s confidentiality and grievance policies to the client;</td>
</tr>
<tr>
<td>• establishing the client’s eligibility for services (which can include HIV status and other criteria);</td>
</tr>
<tr>
<td>• if there is an immediate need, securing permission from the client to release information, based confidentiality and disclosure policies;</td>
</tr>
<tr>
<td>• establishing whether the client needs a range of services and support or is interested only in a discrete service;</td>
</tr>
<tr>
<td>• collecting any regional or national or agency-required data for reporting purposes;</td>
</tr>
<tr>
<td>• begin to establish a trusting client relationship while completing the client intake form, collecting basic client information, and starting to explore priority needs;</td>
</tr>
<tr>
<td>• establishing guidelines for matching staff to clients;</td>
</tr>
<tr>
<td>• establishing a system for referrals to other services if needed.</td>
</tr>
</tbody>
</table>

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**Family Case Management – comprehensive, short and long-term**

*Lesson: Pilot projects have demonstrated the feasibility of deinstitutionalizing children and using a case management approach to support long-term, family-based care.*

A number of governments, including those in the former Soviet system, have responded to the tremendous disruptive influences of unemployment, migration, and social vulnerability to alcoholism and substance abuse by designing social support systems for families. Educators, health care workers, and social workers are trained as child and family advocates to help families access state structures and donors. Family-centered support systems are composed of a range of services, including: child and family assessments, strengthening family support networks, obtaining child identity documentation in order to access child services, provision of books and supplies or school fees to promote school attendance, addressing stigma and discrimination against single parents, assistance with family-specific problems (relationship problems, domestic violence, child neglect or abuse, etc.), etc. HIV-positive parents are trained in child development, skills specific to raising children while living with HIV, and how to address child-specific problems and issues. These family-specific services are augmented by referrals to related support services, such as medical care, employment assistance, temporary shelter, or permanent housing assistance.

*Illustrative Case Study:* UNICEF and the Ministry of Education invited EveryChild to pilot a family-based care model in Georgia (Tolfree, 2006). The goal of the project was to return children living in residential care to their families and to determine the kind of services that could ensure sustained family-based care. Following four months of intensive training, social workers used a case management approach developed by technical advisors with regional and international expertise. On-the-job supervision was a critical element.
of implementation of individually tailored case management assistance plans in order to ensure that a full range of community support services were utilized and that high quality family-based care matched the needs identified during assessment. The pilot project was assumed under the Ministry of Education and expanded to other parts of the country, and deinstitutionalization is a priority of the new state child welfare policy.

Lesson: Models for community-based case management should be flexibly responsive to the varying levels of client need, client readiness, and health and social service agency resources. Clear case management standards are critical in order to define minimum agency requirements for case management and to ensure uniformity and continuity of care as clients’ circumstances change over time.

**Case Management Standards**

State health departments throughout the United States provide HIV case management services for families and children; these services are funded by state and/or federal grants and are provided in a variety of settings, including community health centers, hospitals, or community-based organizations. The AIDS Institute of the New York State Health Department currently funds two different models of case management services that are meant to be provided sequentially:

I. **Supportive case management**

This model is responsive to the immediate, time-limited needs of a person living with HIV, including those persons who have completed comprehensive case management but still require a maintenance level of periodic support from a case manager or team. The goal of these services is to meet the immediate health and psychosocial needs of the client, at their level of readiness, in order to restore or sustain client stability, and to begin to develop a supportive relationship. The core set of activities within this model are focused on follow-up by the case manager or team to ensure services have been received and to help assess whether additional or different services are needed. Clients experiencing a repeat cycle of a crisis or problem are usually referred to comprehensive case management, depending on their level of readiness to participate.

II. **Comprehensive case management**

This is an intensive, proactive, long-term level of case management service provision, designed to serve persons living with HIV with multiple complex psychosocial and/or health-related needs, and their families/close support systems. The goal of these services (which can be provided by a single case manager or by a case management team) is to address client needs for concrete services such as health care, entitlements, housing, and nutrition, and to develop the relationship necessary to assist the client in addressing other issues such as substance use, mental health, and domestic violence, in the context of their family or close support system. The core set of activities within this model are focused on developing service plans to meet the client’s needs, helping clients to access and navigate multiple service systems (including negotiating and advocating for specific services and coordinating services), and to provide general education and supportive counseling. This model requires a high level of participation by the person living with HIV.
Case management is a multi-step process to ensure timely access to and coordination of medical and psychosocial services for a person living with HIV and, in some models, his or her family/close support system.

The goal of case management: To promote and support independence and self-sufficiency. As such, the case management process requires the consent and active participation of the client in decision-making, and supports a client’s right to privacy, confidentiality, self-determination, dignity and respect, nondiscrimination, compassionate non-judgmental care, a culturally competent provider, and quality case management services.

An additional goal of case management with families caring for HIV infected or affected children/youth: To maintain and enhance the effective functioning of the family and to support parents in their care-giving role. Case management services to children must be matched to their age and developmental level, enhance functioning and growth, and include children’s participation in decision-making, as appropriate to their age and abilities.

Intended outcomes of HIV case management for persons living with HIV:
- Early access to and maintenance of comprehensive health care and social services.
- Improved integration of services provided across a variety of settings.
- Improved referrals to TB, substance treatment and recovery, in relation to navigating multiple service systems.
- Enhanced continuity of care.
- Prevention of disease transmission and delay of HIV progression.
- Increased knowledge of HIV disease.
- Greater participation in and optimal use of the health and social service systems.
- Reinforcement of positive health behaviors.
- Personal empowerment.
- An improved quality of life.
Practical Implications: These two case management models are implemented throughout the state of New York through a series of uniform processes, each of which are guided by specific case management standards, basic information provided at each stage, timeframes, status updates, eligibility criteria, guidelines for staff conducting and/or supervising case management, and other criteria for successful completion of each process. Guidelines and standards have been developed for each of the case management processes listed in the following box:

<table>
<thead>
<tr>
<th>Key Case Management Components</th>
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<tbody>
<tr>
<td>- brief intake/assessment process</td>
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<tr>
<td>- selection of case management model and placement</td>
</tr>
<tr>
<td>- brief service plan</td>
</tr>
<tr>
<td>- initial comprehensive assessment</td>
</tr>
<tr>
<td>- initial comprehensive service plan development</td>
</tr>
<tr>
<td>- service plan implementation, including client contact, monitoring and follow-up</td>
</tr>
<tr>
<td>- reassessment</td>
</tr>
<tr>
<td>- service plan uptake</td>
</tr>
<tr>
<td>- case coordination and case conferencing</td>
</tr>
<tr>
<td>- crisis intervention</td>
</tr>
<tr>
<td>- case closure (including transition and discharge)</td>
</tr>
</tbody>
</table>

Documentation throughout either model of case management includes proper client consents and authorized releases of HIV confidential information to service providers as required by law.

Both case management models rely on trained staff that is appropriately trained; capable and empathetic; able to conduct interviews that put clients at ease; obtain key personal information; discuss sensitive topics in a way that is empowering of each client; recognize potentially urgent situations; and adhere to confidentiality and release of information policies and procedures. Continuity of care is preserved as clients move flexibly from one model to the other, depending on changing needs; policies and procedures describe the process by which clients are monitored for progress, periodically re-assessed, and move between the models.

Lesson: In a number of countries with integrated systems for care and support of children, social service departments and health departments have worked closely together to develop systematic ways of analyzing, understanding, and tracking progress of children and young people within their families and the wider context in which they live. Assessment of needs for support services should be founded in a working framework that is child centered, is rooted in child development, ensures equality of opportunity, involves children and families, and is carried out as a continuing process (not a single event) in parallel with other service provision.

Illustrative Case Study: In the United Kingdom, the Department of Health organized four groups, including the Social Care Group that is headed by the Chief Social Services Inspector and Head of Social Care Policy. In 2000, the Department of Health issued a framework document jointly with the Department of Education and Employment and the Home Office; the framework is the cornerstone to a series of accompanying guidance and training materials to systematically assess the needs, the risk to harm, and what actions and services can best meet the needs of children and young people within their families (Department of Health, 2000). The framework was produced to guide social service departments, local authority services, health authorities, and youth justice services, reducing unnecessary duplication of child assessments among...
agencies, improving communication, and increasing local confidence in coordinated referral and inter-agency work. Ultimately, the contributions of these government departments, statutory and voluntary agencies, academics, and practitioners are meant to ensure promote and safeguard children’s welfare while integrating work across agencies to effectively respond to different types and levels of need, and to produce a unified and timely service response. Nowhere is there more need in England than among the approximately 4,000 poorest neighborhoods (Social Exclusion Unit, 1998).

Recognizing that many families are stressed, the government established a National Family and Parenting Institute to raise public awareness about the importance of good parenting practice, to provide parent support services, and to carry out a research agenda to inform the government during modernization of the National Health Services. The partnership between families (parents) and state services is established in the Children Act of 1989.

The following framework is used as a conceptual map to gather and analyze information about children and their families, distinguishing between different types and levels of need. Three critical domains (each of which has a number of critical dimensions) inter-relate and influence the child’s situation and welfare (at the center):

1) the development needs of the child;
2) the capacities of parents, guardians, or caregivers to respond appropriately to those needs;
3) the impact of wider family and environmental factors on parenting capacity and the child.

The interactions between the different domains and dimensions are often complex (see diagram on next page), necessitating understanding of the strengths and difficulties within families, the vulnerabilities and protective factors within a child’s world, and the impact of all these factors on the child.


This framework has far-reaching, practical implications for social service
assessments and referrals among child- and family-focused agencies. The framework is the basis for a series of documents providing practical guidance for social service (and a wide circle of other) providers. It begins with the premise that all social service providers must establish inclusive practices for widely diverse children that accommodate different rates or patterns of development, and therefore different development needs. Important influences on a child’s development include genetic factors, the quality of attachment to primary caregivers, social integration of the family, and the quality of everyday life. Issues of race and culture (which fundamentally shape a child’s identity and well being) have to be taken into account during assessment and referral, and intervention and planning. The framework also incorporates the Disability Discrimination Act of 1995 that makes it unlawful to refuse to withhold any service which is provided to the public, provide a lower standard of service, or offer a service on less favorable terms for persons (including children) living with disabilities.

**Referrals to Prevent and Treat Tuberculosis**

*Lesson: An integrated system of coordinated HIV and TB services is central to the multidisciplinary response needed to prevent initial and recurring and multi-drug-resistant tuberculosis among families. Social services play a pivotal role in providing counseling, addressing stigma associated with these diseases, supporting adherence to treatment, and referring children and families in need of prophylactic or comprehensive treatment.*

The World Health Organization’s (WHO) and the U.S. Centers for Disease Control (CDC) have raised recent concerns that the gains made in global TB control are threatened by the emerging threat of multiple drug resistant TB (MDR-TB) and extensively drug-resistant tuberculosis (XDR-TB). XDR-TB is resistant to three or more of the six main classes of second-line anti-TB drugs; both MDR-TB and XDR-TB severely restrict TB treatment options and compromise the progress to date toward universal access to HIV prevention and treatment and global responses to communicable disease preparedness as well (WHO, 2006). In order to prevent further drug-resistant TB, the WHO Global Taskforce on XDR-TB recommends, as a first priority, the immediate strengthening of TB control in countries (detailed in the Stop TB Strategy and the Global Plan to Stop TB, 2006-2015).

The Stop TB Strategy has important implications for using existing social service and support systems, including NGOs and PLHIV support groups, as entry points for an enhanced diagnosis, care, and referral response. The following family interventions are at the core of this community-based HIV and TB integrated response:

1. Testing parents and children at risk for TB. This includes:
   - Children or adults living with HIV, or who have lowered immunity (lowered resistance), to TB;
   - Children, youth, or adults with compromised immune systems due to long-term substance abuse (including alcohol abuse), lack of medical care (for instance, homelessness), or poor nutrition;
   - Children or adults living in extended, close contact with someone who has untreated, active TB;
   - Children or adults from countries, such as the Ukraine, with high rates of MDR-TB (that is, TB infections with bacilli resistant to at least isoniazid and rifampicin, the two most powerful anti-TB drugs);
   - Children or adults living in overcrowded or poorly ventilated conditions, such as in residential care facilities, prisons, immigration centers, nursing homes, shelters, and refugee camps.
2. Treating active TB with first and second line drug regimens in a manner that includes significant individual and family counseling. Adherence to a complete treatment regimen is key to preventing death, relapse, transmission of TB to others, and development of drug resistant forms of TB (MDR-TB and XDR-TB). Social service agencies provide comprehensive individual and family counseling on associated topics such as HIV prevention and treatment, improving personal hygiene, adhering to treatment regimens, the side effects of treatment, and the hygienic preparation of nutritious meals.

Counseling may also help children and families cope with the emotional stress of living with HIV and TB and may help identify and address stigma associated with these diseases. Stigma can result in delayed HIV and/or TB diagnosis, delayed seeking of medical treatment, and delayed behavior changes necessary to prevent transmission to others. Counseling can also elicit the support of the entire family for members coping with stigma and the physical and emotional impact of these diseases.

3. Referring children or adults to appropriate medical help for any of a range of side effects associated with TB treatment, ensuring confidentiality of all information about the family.

Illustrative Case Study: In 1998, USAID’s Quality Assurance Project (QAP) began working in four regions of Russia to improve interdisciplinary care to TB patients, to address TB-HIV co-infection through system practices and coordination mechanisms, and to benefit people living with HIV. The project works with health authorities, and other essential stakeholders in the regions of Samara, Saratov, Orenburg, and St. Petersburg (QAP Technical Report, 2005). Results of a number of situational analyses carried out in these regions as recently as 2005 are also instructive of similar issues in the Ukraine:

- Few persons co-infected with TB and HIV receive antiretroviral therapy because of a lack of drugs;
- While the majority of persons with TB are tested for HIV, TB case finding among HIV-positive persons is weak;
- The care of TB patients with HIV lacks coordination with AIDS centers and primary care institutions, especially in ambulatory settings;
- Infectious diseases specialists at AIDS centers have not received guidance on administering TB-preventive treatment for persons with HIV, so treatment is not given;
- A large portion of people living with HIV are homeless or intravenous drug users who have low awareness of the risk for TB, rendering them unlikely to seek TB testing;
- In a study conducted among TB hospital patients in Samara, Russian Federation during 2001-2, it was concluded that prisons are major drivers of TB and HIV epidemics. Rates of HIV, hepatitis B and/or hepatitis C co-infection were higher in prisoners than in the general population, and about half of the prisoners in the study were drug users, particularly intravenous drug users (Drobniewski et al., 2005);
- While the majority of TB patients are tested for HIV in hospitals, TB case finding among HIV-positive patients is weak or non-existent;
- AIDS Centers, ambulatory care centers, and primary care institutions do not collaborate to coordinate the care of persons who are co-infected with TB and HIV, so opportunities for TB prophylaxis and referral to ART are missed;
- Social protection services have little appreciation of the issue and are largely uninvolved in the process of support for persons with TB and/or HIV;
- Few if any community-based organizations exist to support persons with TB.
Practical Implications: In 2002, the government of Russia established the Federal TB Healthcare Delivery Center for HIV-Infected Patients (under the Ministry of Health), and a high-level Working Group on TB has recommended creation of the position of TB-HIV care coordinator at the national level. Three-day training regional seminars have been delivered for regional TB specialists who are responsible for treatment coordination of persons co-infected with TB and HIV. Training focused on TB detection, TB treatment and prophylaxis in persons living with HIV, and coordination between TB and HIV/AIDS services. In 2004, a national TB-HIV workshop was held among the Russian Ministry of Health and Social Development, the Federal AIDS Center, and the Federal Center of TB Care for HIV-Infected Patients (with WHO support) in order to analyze the situation and determine appropriate TB-HIV collaborative interventions, including a joint plan for TB-HIV control.

The design of a HIV treatment, care, and support system is being initiated in the four regions of Russia through an approach that includes providers from TB dispensaries, AIDS centers, polyclinics, drug clinics, the prison system, social support services, and community organizations. The objectives of this initiative are focused on identifying feasible solutions for “weak” points that prevent effective delivery of care to persons co-infected with TB and HIV; developing a system that ensures all persons living with HIV receive TB services, including preventive treatment; and developing a system that ensures all persons with TB know their HIV status and receive ART if appropriate. Fundamental to this interdisciplinary approach is improved linkages and quality assurance mechanisms between healthcare delivery organizations, social protection and other services, and community-based organizations.

Drug use and imprisonment are important risk factors for the spread of HIV and TB. Co-infection with HIV and TB, especially MDR-TB is becoming a deadly combination. It is becoming widely recognized that prisons should be one of the main sites for detection and treatment of TB/HIV co-infection and HIV risk reduction activities. Improvement of treatment adherence is essential to prevent resistance to TB and antiretroviral drugs.

Referrals to Treatment for Substance Use

Just as substance use by one member of a family affects the entire family dynamic, the long-term, step-wise process of risk reduction, treatment, recovery, relapse prevention, and ongoing management of substance use will deeply involve all family members. Added factors, such as maternal or paternal substance abuse and/or HIV infection, compound each other to increase the risk of abandonment, poor quality of care, and/or neglect of especially infants and toddlers, and risk of orphan hood.

The concept of “continuous quality improvement” is being employed by a number of countries in order to improve the effectiveness and treatment outcomes of the clinical management of substance abuse. The UK, Northern Ireland, and Scotland have developed evidence-based clinical guidelines and new systems of clinical governance through a consensus process from a wide source of medical and non-medical agencies and individual professionals (Department of Health in Scotland, Wales, and Northern Ireland, 1999). The current drug treatment policy is based on various publications and strategies, including a 1996 Effectiveness Review (UK) that identified a dual role for General Practitioners in the treatment of drug misuse. General Practitioners provide general medical services and identify and treat drug misuse, including referring to specialist drug services, promoting harm minimization, and sharing care with a specialty drug treatment service provider (the concept of “shared care” is further discussed below).

The clinical guidelines are based on the premise that “there is also increasing evidence that treatment (medical and social) is effective in maintaining the health of the individual and promoting the process of recovery” (pg. 6) and that “there is good evidence that harm minimization approaches have had considerable
success in reducing the rate of Human Immunodeficiency Virus (HIV) among injectors in the drug misusing population” (pg. 7).

A number of countries (and states in the U.S.) have established laws providing public assistance to families coping with HIV and substance use and to abandoned infants. In the U.S., the Abandoned Infant Assistance Act (AIA) funds 36 programs to 18 states and the District of Columbia, including establishment of a National Resource Center. AIA project goals are to prevent abandonment and promote permanency, well being, and safety for children affected by substance use and/or HIV/AIDS. The AIA program seeks to meet the human service needs for all family members, to help them overcome physical, developmental, and emotional effects of substance use, poverty, and HIV/AIDS (National Abandoned Infants Assistance Resource Center, 2006). Communities with AIA programs are reporting reduced incidence of abuse and neglect of infants, and decreases in length of time children board in hospitals (because no alternative care giving arrangements could be identified). Women participating in AIA programs are less likely to use drugs or alcohol and are more likely to be employed. AIA programs collaborate with social services and legal programs to assist parents with HIV to develop custody plans for the future care of their children.

Lesson: The concept of “shared care” and the role of social services in interdisciplinary approaches providing clinical and psychosocial support to individuals and families affected by substance use are highlighted in a number of national guidelines for the management of substance abuse.

There is increasing international agreement that a broad, multidisciplinary approach and a wider community perspective is needed to successfully address emerging patterns of substance use and to provide the full array of treatment, rehabilitation, and prevention services included in the management of substance use. In 1999, clinical guidelines for management of drug use/misuse were published within the United Kingdom’s National Health Service (Department of Health in Scotland, Wales, and Northern Ireland, 1999). It describes the concept of “shared care” as: “The joint participation of specialists and general practitioners (and other agencies as appropriate) in the planned delivery of care for patients with a drug misuse problem, informed by an enhanced information exchange beyond routine discharge and referral letters. It may involve the day-to-day management by the general practitioner of the patient’s medical needs in relation to his or her drug misuse. Such arrangements would make explicit which clinician was responsible for different aspects of the patient’s treatment and care. These may include prescribing substitute drugs in appropriate circumstances. A number of specific factors and features, relevant to the treatment of drug abusers/misusers, accounts for the development of shared care. They include:

- Shared care is a rational model to improve service delivery: it aims to deliver a flexible service, utilizing differing skills in the most effective manner.
- The general shift towards a better balance of primary and secondary health care provision with the emphasis being placed on a primary-care-led National Health System.
- An increasing preference by drug misusers to receive care in a primary care setting in the community wherever possible.” (pgs. 10-11, Guidelines on Clinical Management)

Social workers carry out a critical role in community-based and residential care for persons and families coping with issues of substance use and recovery. In Scotland, Wales, and Northern Ireland, social workers are based at local authority Social Service Departments and are particularly involved when there are child and family care issues which place children in vulnerable situations. At least one social worker from each local authority has responsibility for coordinating social work responses and resources and/or participate on specialist multidisciplinary “drug misuse teams.” Since the National Health Service and Community Act of 1990, social workers are also involved in allocating the provision of longer-term residential rehabilitation and non-residential care as part of their community care assessments of families affected by substance use.
These practices extend to (separate) children’s and young people’s services, and treatment and recovery services. Such services are sensitive to and appropriate to the specific needs of children and young people in a service environment that is also appropriate to their age. Social workers determine interventions based on a comprehensive assessment of need, developmental maturity, family factors, and risks of substance-related harm.

**Lesson:** Since 1991, the U.S. Department of Health and Human Services (DHHS) has funded family-focused projects through community-based organizations, university affiliated organizations, or public agencies throughout the country. The projects’ successes are predicated on concurrently addressing the needs of the entire family in order to positively affect the well being of children.

AIA programs vary in length and duration of services provided. Some projects provide direct substance abuse treatment services, while others work closely with treatment providers and provide ongoing recovery support and relapse prevention. The programs assist families in accessing treatment and the many ancillary services they need, and a subset of projects work on custody planning for families with young children affected by HIV. Assistance is provided with legal, medical, recreation, psychosocial support, and support for relatives who are caring for young children affected by substance use and/or HIV. Regardless of the service and support mix, all AIA programs use a home-based interdisciplinary approach and case management to coordinate and track quality service delivery and outcomes.

**Illustrative Case Study:** Operating since 1991, the Coordinated Intervention for Women and Infants (CIWI) is an AIA-funded program of the Department of Child and Adolescent Psychiatry, Yale University School of Medicine. The department CIWI provides case management services and intensive, voluntary in-home clinical parental guidance. Women served by the department’s CIWI have current or recent histories of substance abuse and are either pregnant or have a child under one year-old; most of the families are low-income, but the number of middle-income families receiving services is increasing. Over one-fourth of the women served are single heads of households, and many of the women are victims of domestic violence. The CIWI developed a manual that describes specific interventions in areas such as child development, parenting skills, home safety and cleanliness, substance abuse treatment, and child’s language development.

The majority of women participating in the CIWI program are referred from the Department of Children and Families (DCF). The program team, a master’s level licensed social worker and a bachelor’s level mental health counselor, visit each family in their home for a minimum of two hours weekly, first developing a therapeutic relationship with the mother (during the first month) and performing a functional assessment of the mother-child dyad and any siblings. Since the goal is to ensure the safety and well being of children and the stability of their caretakers, subsequent visits engage the family and team to work together towards agreed upon treatment goals. The team also helps the family connect to community agencies to access other services, coordinating closely with pediatricians and others. A bi-weekly case review is held at the DCF office to bring representatives of community service agencies together with the home visitation team to review the treatment and recovery plan and progress for drug-involved mothers and their children.

Success is measured by the degree of placement stability for the infant (and siblings) and the ability of the mother to meet basic and specialized needs of family members, to enter into substance treatment and recovery, and degree of parenting effectiveness. This data is captured for both program evaluation and to continually improve the clinical work. The program has been so successful that DCF is replicating the CIWI model throughout the state of Connecticut.

**Support for Caretakers, “Respite Care”**
“Respite care” or “care for the caretakers” is a fundamental part of social service delivery, allowing parents and caretakers who are stressed or in turmoil a temporary period of relief as a reprieve. Respite care for families with HIV-related conditions provides attention for the child and much needed rest or support for the parent or caretaker. According to the U.S.-based National Resource Center for Respite and Crisis Care Services, the newest groups of families in extraordinary need of respite care are those with children living with HIV-related conditions. HIV is intergenerational, effecting one or both parents and children (most frequently through mother-to-child transmission of the virus), and frequently overwhelming a family. Parents may only learn of their HIV status after the birth of a child who tests positive, thus throwing their relationship into crisis at the time when stability and support are most needed by the child/children. And parents with HIV-related conditions may have diminished physical and emotional energy for care of their children. Due to the incapacitation, chronic illness, or death of parents, children with HIV-related conditions or affected by HIV in their family can find themselves living with elderly grandparents who have their own chronic health problems and economic insecurity. Others may live with foster parents who also become overwhelmed by the myriad of needs of the child. These families – biological, extended, foster – may not seek childcare assistance because they are unwilling to disclose the HIV status of the child or members of the family. Parents caring for medically fragile children are in grave need of respite care which may be critical to the long-term stability of their family.

Respite care services for families or caregivers with a child living with HIV or a medically fragile child provide support on both an emergency and long-term basis. They provide in-home trained staff or volunteers to assist and alleviate a parent by providing child care or taking the child to a social activity. The respite caretakers are trained in medical, emotional, and practical issues of caring for children living with HIV, including maintaining confidentiality for the child and the family. Staff is usually affiliated with home health care, respite care, or a foster care agency; volunteers are also affiliated with agencies and are typically reimbursed for expenses. All staff and volunteers are required to have background checks for history of child abuse or neglect, a medical exam, and training.

For in-home providers, supervision is provided through a combination of telephone calls and a monthly support group meeting that offers an opportunity for peer supervision and support. A sample of issues that are discussed during staff and volunteer support groups includes:

- Answering children’s questions about loss and their own or their parents’ future;
- Setting appropriate role boundaries with the parents;
- Resolving cross cultural issues, such as discipline styles or extended family care arrangements for children who may be transferred back and forth between families.
- Coping with grief and despair at the magnitude of the child’s and family’s many issues and problems.

**Illustrative Case Study:** Parents of young, perinatally HIV-infected children often report difficulty administering prescribed antiretroviral therapies that require combination therapy with multiple daily dosing. Frequently, pediatric-friendly formulations are not available. A clinical intervention tested among pediatric patients with HIV and their parents (at St. Jude’s Children’s Research Hospital) consisted of pill-swallowing training (PST). The training sessions were conducted by a pediatric psychologist and involved procedures including swallowing pieces of "gummy worm" candy, and then various placebo gel caps of increasing size. Six months after the training, the young children with perinatally acquired HIV showed a significant improvement in medication adherence, and an improved immunologic functioning as measured by CD4+ T cell percentage and in viral load (Garvie et al., 2007).

The utility of this training has implications for improved parent-provided support and standards of care of young children with HIV. Parents are taught to coach and encourage their children in the process of pill
taking. It also has cost-reduction implications as compared to the costs of nonadherence to a treatment regimen. The technique relieves parents of stressful treatment administration sessions with their children and improves child compliance.

**Peer Support and Self-help Groups**

Children, youth, and families with HIV face many challenges that can be met with information, guidance, and the support of others similarly affected by this highly stigmatized chronic illness. As people with HIV are living longer, healthier lives, new concerns are emerging which include the effects of HIV on development, the long-term effects of medications, coping with HIV-related disabilities, learning problems, and body image and depression in adolescents. All of these are long-term factors that can determine the quality and well-being of individuals and families living with HIV. Individual and group support are important components of the overall family treatment plan; they can take many forms, for example, professional or peer-led self-help groups, parenting groups, Alcoholics Anonymous or other 12-step programs. As with all other aspects of HIV-related family care, support groups should be guided by the principles of child and other family member protection, standards of confidentiality and parental consent, inclusion and equal opportunity, and health and safety. This includes establishing healthy boundaries and codes of conduct to help ensure that children and family members with HIV will feel valued, build confidence and life skills, and thrive independently, rather than developing dependent relationships within the group.

“Before I was very alone. I had no one to talk to and I felt that my life was going to end. I’m getting more confident and I’m beginning to learn to cope.”
- Alice (aged 16, HIV positive, in Body and Soul, 1998)

Parents and caretakers can benefit from specific support groups organized to address their specific issues in the context of living with HIV, issues which in turn affect the entire family system. Information and support to work on parents/carers’ dilemmas, fears, guilt or sense of shame, burdens of care, and to clarify thinking can greatly benefit the parent-child relationship. Support groups can also help to address societal and community stigma that influences both parent and child self-esteem and attitudes (National Children’s Bureau of the UK, 2006). Ongoing support groups provide a learning environment in which to explore issues of ill health and the effects on children and family, bringing up children, supporting children with a chronic illness due to HIV, talking to children/adolescents about HIV and sex, and other issues determined by the group on an ongoing basis.

Support groups can take many forms. Groups may be developed for people who have certain characteristics in common; for instance, groups for HIV-positive women (and/or men), people of color, children, teens/adolescents, older adults, prisoners, or people with specific sexual orientation or identity. Other groups are formed around specific concerns, for example, for long-term survivors, people managing co-infection (HIV with TB or Hepatitis), newly diagnosed individuals, and for people living with HIV who are in recovery from drug and alcohol abuse.

Support groups address social, emotional, educational, and medical concerns and also provide social and recreational outlets. They can reduce social isolation while enhancing empowerment, helping individuals and families to identify their strengths, resilience, and abilities to cope with a chronic illness like HIV. Frequently, these groups are the “safe spaces” in which single parents, HIV couples, serodiscordant couples (where one person is HIV-positive and the other is HIV-negative), and other caretakers living with HIV can discuss their HIV status and come face-to-face (sometimes for the first or only time) with other people who
are positive. Because HIV is accompanied with stigma, issues that are identified as common among members of a peer or other support group are normalized (rather than being experienced as unique); this can be a first step towards believing and being able to devise ways to meet those common challenges. Living well with HIV usually requires behavior changes that can be initiated, encouraged, and reinforced within support group settings.

Illustrative Case Study: In Romania, a peer support group for HIV-affected parents was implemented by Holt International (Dragomir, 2002). The program, “How to Become Better Parents”, was established at the Resources for Parents Center in Bucharest to provide training and support for a variety of parents, including parents caring for HIV-positive children. As a result of the peer support group, parents reported improved ability to cope with stress, better understanding and ability to fulfill their roles as parents, and improved ability to build support networks. This program is one practical indication of the importance of appropriate models of peer development and the positive impact that they can have on the lives of HIV-affected parents.

Additional Illustrative Case Study: A group support and outreach program, “Voices of Positive Women”, was designed to address the needs of women and children living with HIV in Ontario, Canada. The program targets family-related issues such as disclosure to children, guardianship, disclosure to schools, parental relationships, updated pediatric medical issues, caring for the family when one or more member is not well, and accessing practical support. The peer support group meets monthly, with members traveling from as far as 60 miles to attend. The program includes a mothers-only retreat to discuss issues of HIV, self care, and spirituality. Annual events include a “Family Farm Day” as an opportunity for spouses and the entire family to connect, and childcare and transportation are provided.

The support group is successful in that it is in its third year of operation and developed into a complete social network for HIV-positive mothers from 55 families. Many members also provide each other with practical support such as regular telephone calls and correspondence, child care, meal preparation, and housework. The group now encompasses over 55 families living with HIV in Ontario. Many of the women have now joined their local AIDS Service Organizations and are actively helping others.

Families with Children Living with Disabilities

In most developed countries, a HIV diagnosis of stage 3 or 4 of the illness can be the basis for legally qualifying as a “person living with a disability” (for example, in the UK, other European countries, Canada, the US, and elsewhere). This status confers important legal protection from discrimination on the basis of the disability, i.e., HIV, including exclusion from social or medical services, or denial of benefits. It also provides opportunities to access services, special social security benefits for people living with HIV who are unable to work, and supplementary income or food stamps for families with HIV with low household income.

Countries have less thoroughly addressed the needs of doubly disabled persons who are living with HIV and an additional physical, psychological, or emotional disability. These dual conditions compound the stigma associated with each, and increase the challenges faced by persons living with HIV of all age groups. The impact on children and youth at a time in their lives, when they seek to be most like their peers, can be devastating, and can become a huge source of stress for families. HIV programs need to be responsive to the needs of disabled persons (e.g., providing HIV prevention information in Braille), including the development of support groups for persons living with HIV who are doubly disabled.
Lesson: In order to ensure specialized service approaches meeting the needs of children living with disabilities, national child- and youth-focused strategies must include specific standards for disabled children and their families.

In the United Kingdom, the National Service Framework for Children, Young People, and Maternity Services includes eleven standards for promoting the health and well being of all children and meeting their service needs. The eighth standard focuses on: “Disabled Children and Young People and Those with Complex Health Needs” in order to address the needs of children and young people (and their families) living with learning disabilities, autistic spectrum disorders, sensory impairments, physical impairments (including HIV), and emotional/behavioral disorders. The standard is stated as follows: “Children and young people who are disabled or who have complex health needs receive coordinated, high-quality, child- and family-centered services which are based on assessed needs, which promote social inclusion, and, where possible, which enable them and their families to live ordinary lives” (Department of Health, 2004).

Access to social services in the UK for the complex array of needs associated with a wide diversity of disabilities is based on “threshold criteria” that are determined by local authorities in partnership with health, education, and voluntary sector providers. The criteria are based on the impact the disability has on the child and family, and the need for services that will support optimal family life and optimal child development. Children living with disabilities and their families, including those living with HIV, are involved in decision about service planning, commissioning services, and re-design of the plan as the situation changes. Services include suitable, adapted housing, assistive technology, alternative communication systems, physiotherapy, occupational therapy, speech and language therapy, etc., and that these needs continue to be met if the child lives in a foster care family. Support services are also available for parents, since families with a disabled child and families with children living with HIV experience high levels of stress. Fathers are often alienated or feel excluded during certain aspects of their child’s care, so support and increased opportunities to access services can contribute to fathers becoming more involved in childcare and to positive outcomes for the entire family.

Under the UK Carers and Disabled Children Act 2000, local authorities, the Primary Care Trust, and the National Health Service Trust have also developed a direct payment service for children living with disabilities and their families. This measure reinforces independent decision making, choice, and control over the way children’s social services are accessed and delivered (Council for Disabled Children, 2004).

The impact on staff of multi-agency approaches to the care for children living with disabilities has been studied, including a three-year qualitative research study in which interviews with 115 professionals were conducted (Abbott et al., 2005). It concluded that staff were overwhelmingly positive about working as part of a multi-agency service and reported improvements in areas such as professional development, communication, collaboration with colleagues, and relationships with families with disabled children. Other studies considered the input and direct experience of children living with HIV and other disabilities and their families as service users (UK Audit Commission, 2003). These studies provided recommendations for service improvement, and overviews of good service practice, a selection of which are presented here:

- Children and young people living with HIV and other disabilities, their parents and caretakers are involved in changing the local map of services in some areas, through a range of different consultation groups and processes that involve users seriously.
- A number of localities have a forum where representatives from health, social services, education, leisure/recreation and the voluntary sector share information and are starting to agree on a shared vision of services for children living with HIV and other disabilities, and their families.
In some areas, agencies work together and organize joint teams of staff and care coordinators around the needs of individual children living with HIV and other disabilities, and their families.

The United States Congress reauthorized the Education for All Handicapped Children Act and renamed it the Individuals with Disabilities Education Act (IDEA, Public Law 101-476) in 1990. In addition to access to education, these federal regulations specify the related services, defined as “transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education” (Section 300.24(a)). The following are included within the scope of services for children living with HIV and other disabilities:

- speech-language pathology and audiology services;
- psychological services; physical and occupational therapy;
- recreation, including therapeutic recreation;
- early identification and assessment of disabilities in children;
- counseling services, including rehabilitation counseling;
- orientation and mobility services;
- medical services for diagnostic or evaluation purposes;
- school health services;
- social work services in schools;
- parent counseling and training; and
- transportation. (Section 300.24(a))

Social services provided to children and young people living with HIV and disabilities in school settings are meant to help students benefit from his/her educational program. It might be necessary to address issues or problems at home or in the community that adversely affect a student's performance, attitudes, or behaviors at home and at school. Social work services in schools include:

- “preparing a social or developmental history on a child with a disability;
- group and individual counseling with the child and family;
- working in partnership with parents and others on those problems in a child's living situation (home, school, and community) that affect the child's adjustment in school;
- mobilizing school and community resources to enable the child to learn as effectively as possible in his or her educational program; and
- assisting in developing positive behavioral intervention strategies” (Section 300.24(b)(13)).

**Orphaned or Abandoned Children**

While a family is central to the optimal growth and development of a child, there are wide ranging circumstances that prevent children living with or affected by HIV from living with their nuclear families. These circumstances include the multiple and interactive impacts of HIV, poverty, substance use, disability, and imprisonment. While primary prevention of child abandonment and neglect is ideal, the reality for many children is a search for family-like settings that will provide relief, protection, care, support, and nurturance.

**Children’s Homes/ Residential Care (orphanages, family model residential care)**

*Lesson: In countries that have been undergoing a transition to market economies (such as much of Central and Eastern Europe and the former Soviet Union), there has been an over-reliance on institutional care for marginalized and vulnerable individuals, including poor, neglected, or disabled children; this model of care*
utilizes a disproportionate amount of the (limited) government and non-government resources that are needed in order to establish community-based social services. The community-based model of care has been found to be cost-effective in industrial nations.

A review of residential care throughout the region (Tobis, 2000) found discrimination on the basis of disability, gender, and ethnicity behind most practices of institutionalization. For example, in Bulgaria, Roma people comprise approximately 9 percent of the total population but almost 70 percent of children in institutions. Hungary, Lithuania, Poland, and Romania are among the few countries that are developing or planning for national systems of community-based services as a way to prevent institutional placement.

**Illustrative Case Studies:** Although most of the programs were in small scale, pilot phases, two are illustrative of the paradigm shift from institutional care to a range of new program options:

*Family Support Center*, Albania (Shkodra). Established by Save the Children/Denmark, the center opened (in 1996) to assist families with children in risk of institutionalization. The center has two social workers who assist 10 families with children by providing food, education, home visits, parent training, and help with school work. In its first year and a half of operation, the program identified 4 children in local infant and children homes who could return to their families. By 1998, the General Administration of Social Services began paying the recurrent program costs.

*Support for Families in Especially Difficult Situations*, Romania (2 counties and Bucharest). With assistance from UNICEF, the Commissions for the Protection of Minors established programs to assist families whose children were at risk of institutionalization. Two to four government social assistants were trained at each site to counsel families, conduct social work home visits, and place children into foster care who could not remain safely with their families. Some programs reported that families needed more material assistance than they could provide adequately.

**Practical Implications:** On the basis of this regional study, Tobis suggests a 6-step strategy for the region:

1) Change public opinion and mobilize community support;
2) Strengthen community-oriented social welfare infrastructure;
3) Establish community-based social service pilot projects;
4) Use pilot projects to reduce the flow of individuals entering residential institutions and to reintegrate individuals into the community.
5) Redesign, convert, or close facilities.
6) Create a national system of community-based social services.

*Illustrative Case Study: Family-based Childcare Model – SOS Children’s Villages.* The SOS Children’s Village model has been applied in 131 countries worldwide since World War II (the first village was founded in 1949 in Austria); the SOS villages, community homes, and social centers are positive alternatives to institutionalization, and also serve as complementary interventions to prevent child abandonment. The organization is an independent, non-governmental social development organization, which works in the spirit of the UN Convention on the Rights of the Child and pioneered the definition of “family focus” in the long-term care of orphaned and abandoned children and child abandonment prevention. Operating from the premise that the family is the center of society, SOS Villages are typically villages of 10 to 15 houses. Children are accepted from small babies until the age of ten, unless there are siblings involved, in which older siblings would also be accepted. The children grow up together in a home that is headed by an extensively trained primary caretaker, usually a “mother”, supported by educational coworkers and “aunties” who are still in training to be SOS Children’s Village mothers.

Each home has a familiar atmosphere that encourages bonding within each family, so that children not only receive shelter but also a sense of belonging. The village provides the context for an extended family
community, providing children with cultural roots and a bridge to the surrounding local community at large. The model is an open living model that promotes integration of SOS Children’s Village children into the local district and supports interaction with neighboring communities. SOS Children’s Village life emphasizes preparation of children for life after leaving the village, so that they can be fully integrated into their local community and are prepared for employment opportunities. In order to ensure a chain of care and support, the SOS Children’s Village is connected to a range of Secondary Facilities, including kindergartens, social centers, medical centers, schools, youth facilities, and vocational training centers. These facilities and adjunct programs are intended for use not only by children from the SOS Children’s Village but also the general public, so that families communitywide have improved social conditions over the long-term.

**Illustrative Case Study: “Grannies” Childcare Model.** The Early Intervention Program in Bulgaria, developed by The Worldwide Orphans Foundation, matches at risk children in orphanages with retired women in the community, affectionately called “grannies”, in order to provide loving care and assistance to promote the growth and development of children. The program intervention is based on the premise that “children lose one month of developmental skills for every three months they live in an institution” (WWO Annual Report, 2005). The grannies are selected, based on their backgrounds in child care, elementary education, or health care and are assisted by a psychologist who helps them provide individualized stimulation and to meet some of the emotional needs of each child in the program. The grannies work for four hours a day, five days a week for at least a year in order to provide an opportunity for each child to develop a real bond and connection with a consistent adult caregiver. Developmental testing of each child in the program was conducted by a psychologist after the first year; results indicated that every child in the program was age-appropriate in developmental skills. Based on these results, the program is being replicated at three sites in Bulgaria and two additional sites in Azerbaijan.

**Additional Illustrative Case Study and Implications:** In Serbia, adolescents are discharged annually from orphanages with little education and no vocational training, due to the ongoing war and conflict. In response to this growing problem, The Worldwide Orphans Foundation developed a project, “Return to the Future Film and Video Project”, to enable teens to engage in a journey of self-discovery about their personal histories while learning film and video skills (WWO, 2005). During the course of the project, teens of the Children’s Home Mladost in Kragujevac, Serbia, visited their home villages to reconnect with family members, neighbors, and friends. They also built skills with digital cameras, video equipment, writing, and editing during their personal history taking experiences. The implications for adolescents with limited education are enormous, since these skills are all useful and marketable skills. Adolescents can learn in a hands-on environment, with support and the technical assistance of a filmmaker, while engaging in vocational training.

**Children’s Involvement in their own care and support systems**

*Lesson: Children and young people are increasingly involved as individuals and via organized groups in decisions about their own care and lives. Their collective participation is increasing their access to information, services, and complaint systems; and increasing their influence over programs and policies affecting them.*

Governments, NGOs, citizens groups, and other support and advocacy groups worldwide are promoting and operationalizing children’s rights in diverse care systems. In some countries, children and youth have formed their own care groups, peer support groups, and are working in partnership with local social services departments.
**Illustrative Case Study:** In the UK, young people formed their own care groups (supported by Save the Children) and children’s rights officers or advocates were appointed to coordinate services and support for children and youth (Tolfree, 2006). A national association of Children’s Rights Officers and Advocates, many of whom were employed by a range of local authorities and NGOs, was established to develop professional practice in children’s rights and advocacy services for children in care. Voices of Care, an organization run for and by children in care, was established in Wales, and A National Voice was similarly established in England. These organizations promote the rights of young people, raise awareness about care issues, address stigma, and inform and influence central and local government agencies within the care system.

**Prevention of Child Abandonment**

Lesson: Rates of child abandonment are reduced through a range of measures that include preventive policies, awareness campaigns focusing on the importance of family care, and support to at-risk mothers.

Many different agencies around the world are working together to help families remain intact and to adequately provide health care and social support to family members, including children, who are living with HIV and other debilitating conditions. There is growing global consensus that flexible strategies are needed to prevent children from leaving their families unnecessarily, and many pilot programs are being tested to support parents, especially single parents (usually mothers) in keeping and caring for their children.

Illustrative Case Study: One pilot project is Save the Children’s “Take Me Home”, a program designed to prevent abandonment of children in Rousse, Bulgaria (Tolfree, 2006). The purpose of this project was to counteract the high rate of institutionalization and inter-country adoption occurring in Bulgaria, especially since the high rate of admissions to infants homes was due to a combination of poverty and stigma associated with marginalized groups (i.e., single parents, children with disabilities, Roma people). The following key steps contributed to a 38 per cent drop in the number of children who were permanently abandoned (and previously available for adoption):

1) A steering committee was formed among representatives from the Ministries of Health, Labor and Social Policy, and Finance at local and central levels, and the non-government organization Save the Children.
2) A survey was conducted among single mothers who referred their children to institutions in order to better understand their needs.
3) The Bulgarian government amended and implemented the Child Protection Act that included the idea of institutional care only as a last resort.
4) Hospital staff and social workers were trained to identify mothers perceived to be at risk of abandoning their infants and to undertake assessments of family situations.
5) Social workers provided a range of interventions (visits, counseling, employment assistance to mothers, small cash transfers to mothers to be able to care for material needs of infants).
6) A media awareness campaign emphasized the importance of children growing up in a family.
7) Day care and outreach support services were strengthened in infant’s homes.

The Take Me Home program was adopted nationally as accession to the European Union was conditional on improvement of the childcare situation. New legislation includes complementary preventive services for children and their mothers.

**Guardianship (biological or extended families, legal protection)**

Lesson: The Prime Minister’s review of adoption and foster care practices (in the United Kingdom) suggested that especially younger children prefer the security of formal adoption (over long-term foster
care arrangements). However there is a special group of children, especially older children, who want to maintain links to their birth families and are in need of alternative legal status to provide greater permanence and security than long-term fostering arrangements. Guardianship provides legal permanence, clear responsibility to a guardian for all aspects of care giving and decision making on behalf of the child/youth, and access to a full range of support service, including financial support.

In the United Kingdom, the Department for Education and Skills (DfES) is guided by a ministerial team, including representatives for children and families, for schools, and for higher education and lifelong learning. This ministerial body also works through Parliamentary Under-Secretaries of State to carry out a five year strategy that is focused on children, learners, parents, and employers in order to “promote personalization and choice” for best care and support of children in different settings (DfES Five Year Strategy, July 2004). The strategy, which relies on the Child Act of 1989 and other legislation, includes goals to extend the period of paid parental leave; measures to improve the quality, affordability and availability of childcare; reform of the regulation and inspection of childcare and early years provision; easy access for every family to integrated services by establishing 3,500 children’s centers by 2010, one in every community; and for school-age children the commitment to provide childcare and other enriching activities on school sites. The strategy is complemented with practical guidance and a quality framework. A wide range of budget streams flow to local authorities who have the responsibility (and flexibility) to carry out the actions implicit in this strategy. The strategy places local authorities, through their Children’s Trusts, at the heart of delivering the new entitlement and in leading collaboration with local learning and skills councils and with schools, colleges, training providers, employers, and universities. It is notable that some funding is earmarked specifically for purposes of collaborative action, including development of common timetables among local authorities and service providers at the community level.

Through the “Every Child Matters” approach, the Department coordinates a multisectoral response, teaming with hospitals, schools, police, voluntary groups, and others, that is shaped by the age and circumstances of children. Improved outcomes for children and young people are accomplished through the multisectoral work of local authorities, including child’s trusts that bring together all services for children and young people in an area (underpinned by the Child Acts of 1989 and 2004). In 2005, Special Guardianship Regulations were introduced along with guidance for social care, welfare, and legal protection of children with guardians (Special Guardianship Regulations, 2005).

Under the provisions of the Child Act, local authorities are responsible for coordinating with other local authorities, health authorities, adoption service agencies, and independent service providers in order that the child/youth within a special guardianship can access the following support services:

- financial support;
- services to enable children/youth to discuss matters relating to guardianship with current guardians, prospective special guardians, and parents;
- assistance and mediation services to enable a child/youth to have contact with parents, relatives, or any other person with whom relationship will result in the well being of the child;
- therapeutic services for the child/youth;
- counseling and information services for the child/youth;
- training for the current guardian or prospective special guardian in order to meet any special needs of the child/youth;
- information for children and guardians so that they can access mainstream services, including social security entitlements and tax credits as appropriate.

Community-based Child Protection
Lesson: Local child centers and hubs can serve as networks to implement national child rights protection laws in a manner that is responsive to each local condition, whether rural or urban. New partnerships between government at different levels and the non-government sector can provide a variety of important services (such as children’s libraries, clubs, and activity centers), especially for poor, marginalized, and vulnerable children. This approach can be extended to work with children in conflict with the law, street children, and in communities where children and their families are affected by HIV, substance use, tuberculosis, and other intersecting issues that provoke a myriad of support and service needs.

Illustrative Case Study: The role of local hubs and centers as physical spaces for children and young people and as points for integration and networking of services has been tested and replicated in China in order to develop child protection services along with children’s participation (Save the Children, 2005). A different type of model has developed in Tibet where school children and youth lead and manage a development group, taking responsibility for health and hygiene in their local village. While adults typically initiate the centers and hubs and work to ensure children’s participation and skills training, the model is unique in that children and young people are now leading research (including research by HIV-affected children on vulnerability), the establishment of new centers, and management of local projects and the centers. Other government-run or sponsored centers, such as street child protection centers, are beginning to link to these existing centers and hubs in order to shift the system of child protection from welfare homes to an array of services, support, and shelter under an integrated child rights programming approach. Child protection services and support encompass protection from abuse (physical violence, emotional abuse, sexual abuse), neglect, exploitation, and from bullying.

Practical Implications: The central implication inherent in centers and hubs is one of the importance of interpreting international covenants on child’s rights and national legislation protecting children into locally-based solutions that are responsive to the needs and vulnerabilities of children who are experiencing massive changes in the social and economic environment. In China, while child protection legislation and commitments against child abuse and neglect are in place, there have not been mechanisms to address such cases; in countries such as the UK with longstanding and supposedly comprehensive child protection systems and qualified and accredited staff, there is an administrative tension between the many government and non-government agencies focused on multidisciplinary and multi-agency responses and the need for a unified approach to child protection. In the Netherlands, one central government agency is responsible for assessing children and referring them to other agencies. In Australia, a Department for Child Safety was established in response to abuses within the foster care system. All of these countries in Europe and Australia are in the process of rethinking the government systems while exploring how to improve the consultation and participation of children and youth in care during development, implementation, and evaluation of all child protection services. This concept of integrated child rights programming (CRP) is a new paradigm driving the coordinated efforts of government and non-government; it rests on the assumption that children and youth and their families be active in local decisions, and that children and youth be supported in establishing and directing their own organizations. The concept of CRP also emphasizes the responsibilities of “duty bearers”, adults who can provide sector-specific expertise (health, education, HIV/AIDS) and who can facilitate an inclusive process of analyzing the circumstances of children and helping to articulate and fulfill programming that protects children’s rights.

The practical establishment of child and youth-owned centers and hubs is necessarily adapted to local conditions, so the idea of a “model” or “blueprint” exists only as an ideal concept. This fact provides tremendous freedom to the adults, children and youth who can essentially create their own culture, values, and methods, social and physical environment for each center. A few basic principles are all-pervasive: that centers are “neutral” places, owned and maintained by all children and youth (not just a subset); that each
Each center acts as a point of referral to other services and support and also as a point of outreach to children in the community who may be marginalized, inaccessible or otherwise invisible, and in need. The center serves as a vehicle to promote children’s participation in other activities outside of the center, reaching out and linking to other agencies across the community (which is the concept of a “hub”). In this way, children and youth are consulted and included in decision making within other community groups and committees. “The hub, as a network of individual staff and agencies that have duties in regard to child protection, is the place where a local procedure can be designed and activated through motivated people.” (page 34, Save the Children, 2005) For example, a local center with many children and youth affected by HIV/AIDS might specialize in providing counseling, advice, referral to services for children, and also be linked to similar support services for adults and families. The hub might develop a series of training for children and their families on issues relevant to improving their quality of life while living with HIV.

Centers and hubs are established on the basis of a set of practical operating principles, including that regular hours are kept so that children and youth know when to access services and activities. Child, youth, and adult relationships are very different in centers as compared to most schools, and activities should be run by children, and supported by adults who are able to encourage participation and child/youth leadership. All center staff have a set of core competencies and additional skills needed to work with children who have been the victims of violence or abuse, are living with disabilities, or who may have behavioral or emotional problems.

**Foster Care – Families Foster Children**

Lesson: While the nature of fostering varies hugely according to the context (e.g., spontaneous fostering by extended families, temporary foster care, long-term formal foster care), the key elements of a foster care system include: selection criteria for recruiting foster carers, training foster carers, identifying children suitable for fostering, matching the needs of the child with the characteristics of the foster family, a phased process of introduction and incorporation of the child into the foster family, and long-term professional monitoring and review in order to assure that the placement is in the best interests of the child.

New working models for foster care have been developed in a number of Eastern European countries in order to provide alternative care options for children living without parental care, many of whom were formerly institutionalized. The development of new models has necessitated capacity building so that centers of social work are re-established and strengthened in terms of both human and material resources.

**Illustrative Case Study:** In the wake of war during 1992-5 in Bosnia and Herzegovina, many children were separated from families or abandoned and living in institutions, or living with families but in substandard living conditions. The Ministry of Labor and Social Policy in Tuzla Canton identified the need to build capacity and to develop a model for fostering that could be promoted locally and nationally (Tolfree, 2006). Working with Save the Children and the Foster Parents’ Association, a fostering model was developed for this context as the principal form of substitute family care. The approach included the addition of a social worker in the Ministry for the first time and a variety of training on fostering, working with families and children, case management, and computing skills. Posters and leaflets were distributed and local community campaigns were launched that involved centers of social work staff and current foster parents, in order to establish guidelines and criteria to recruit new, qualified foster carers. Five three-hour training sessions were developed for foster carers, and the Foster Parents’ Association established self-support networks for foster families and activities for children living with foster families. Procedures were
developed for planning care, reviewing the foster placement regularly, and improving documentation across a uniform, computerized system for tracking the quality of care.

Practical Implications: The model for foster care in the context of Tuzla Canton includes related families (usually grandparents) and unrelated families. Foster care placements are typically long-term and many young people continued to be supported by foster families after they reached 18 years old, even in the midst of starting to exercise more independence. The model consists of the following key elements:
- Recruitment, assessment, selection, and training of potential foster carers, and careful matching of the individual child with appropriate foster carers;
- Situational assessment and care planning for each individual child, ensuring that that process includes full participation of both the child and foster family.
- Phased introduction of the child and foster family so that both are prepared and able to reach consensus with regards to continuing with the placement. At every phase, the child/youth is centrally involved in care planning and reviewing his/her progress with regards to integration and support within a family setting.
- Fostered children are carefully monitored via ongoing visits by social workers. The Foster Parents’ Association similarly supports foster families, helping to resolve any difficulties that might arise.
- Foster children enjoy various social and cultural activities organized by the Foster Parents’ Association and also produced a video, “Do I Have a Right?”

Adoption Services

Lesson: Laws regarding adoption are only part of the appropriate government response to providing child-centered adoption services. Practical guidance that provides algorithms and examples for adoption agencies and that is linked to laws and other regulations are necessary in order to ensure the continued welfare of adopted children and youth.

In the UK, the following legislation and government department orders and guidance provide the framework for both domestic and intra-country adoption services:
- the Adoption and Child Act 2002 makes it clear that the welfare of central importance to all adoption agency and court actions. This Act emphasizes that the needs of children should come before the needs of adults.
- A DfES Practice Guide on “Preparing and Assessing Prospective Adopters” includes providing written information to prospective adopters in the form of a Recruitment Toolkit and a set of adoption leaflets, conducting informational group meetings, and providing one-to-one counseling (with social workers) to clarify the adoption process, eligibility, suitability, and to explore the possible impact of adoption on the lives of prospective adopters. The adoption agency then decides on the basis of eligibility and suitability whether to provide the prospective adopters with a form so that they can make a formal written application. Prospective adopters cannot be excluded due to age, health, disability, or other factors, except concerns about criminal convictions (and there are additional legal requirements for intra-country adoptions). Each adoption agency is required by law to obtain information from the Criminal Records Bureau and other background checks to search for specific convictions outlined in the Adoption Guidance, to conduct three personal reference interviews (including with the current employer and any school officials if the prospective adopter has children), and to obtain a report from the relevant local authority (including social services’ records, education records, and the child protection register) where the prospective adopter lives. Agency decisions to proceed with an
adoption application (or not) are documented on a case record and countersigned by a manager. Prospective adopters must be informed of the agency’s decision verbally and in writing.

The next stage is adoption preparation, with supportive opportunities for prospective adopters to assess their own capabilities and stability of their relationships, and to also learn in detail about children who are likely to be placed for adoption. Critical prospective adopter competencies include: caring for children, providing a safe and caring environment, working as part of a team, self-knowledge about level of own development, and engaging in adoption as a lifelong learning process. In cases where a couple is the prospective adopters, the quality, strength, conflict resolution skills, and commitment to the relationship are important additional competencies. Assessment of the prospective adopter’s capacity to build and sustain close relationships (past patterns of attachment) is part of the basis for predicting future attachments with children. These assessments include examining how conflicts and past traumas or losses are resolved and ability to empathize, or “psychological mindfulness” of others.

Because a child’s positive sense of identity correlates with self-esteem, self-image, and individuality, adoption agencies help prospective adopters gain insight into development of their own identity, in order to support and value development of identity by the child. Many children placed for adoption will have a sense of belonging to another family (a birth family or a previous placement family). Children moving from one placement to another may require additional time and support to recover from these earlier experiences as they move through additional change and uncertainty.

Support is provided through group workshops, tutorials, experiential learning (for example, role plays) sequenced over time. The range of issues to be covered by prospective adopters through a series of modules is listed in the table below (DfES, 2006):

<table>
<thead>
<tr>
<th>OVERVIEW OF THE ADOPTION PROCESS</th>
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<tbody>
<tr>
<td>Part 1: Overview, Assessment Process and Decision Making</td>
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<tr>
<td>Part 2: Matching, Placement and Adoption</td>
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<td>Part 3: The Child</td>
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<tr>
<td>- the difficulties some children experience, such as neglect and abuse, and the effect on their development and capacity to form secure attachments;</td>
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<tr>
<td>- the perspective of the birth family;</td>
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<tr>
<td>- child’s sense of separation and loss;</td>
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<tr>
<td>- child’s contact needs;</td>
</tr>
<tr>
<td>- attachment needs;</td>
</tr>
<tr>
<td>- basic child development.</td>
</tr>
<tr>
<td>Part 4: Skills and Capacities</td>
</tr>
<tr>
<td>Note that in Brazil, the United States, and other countries, potential adopters must complete and “pass” an extensive parenting class.</td>
</tr>
<tr>
<td>- caring for a child who has been traumatized by neglect and abuse;</td>
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<tr>
<td>- understanding and managing health care needs;</td>
</tr>
<tr>
<td>- care for sibling groups;</td>
</tr>
<tr>
<td>- caring for children who come from different ethnic groups with limited information about their past and no birth family contact, especially in intercountry adoption;</td>
</tr>
<tr>
<td>- learning from experienced adopters, including managing stress and developing resilience;</td>
</tr>
<tr>
<td>- understanding the significance of the child’s identity, their birth family, and the need for openness;</td>
</tr>
<tr>
<td>- contact, indirect or direct;</td>
</tr>
<tr>
<td>- equality, including ethnicity, disability, religion, and sexual orientation.</td>
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</tbody>
</table>

A DfES Practice Guide on “Assessing the Support Needs of Adoptive Families” provides good practice guidance for adoption support services that is also based on the child-centered principles of framework (the Framework for the Assessment of Children in Need and Their Families, produced by the Department of Health and partners in 2000 and discussed previously). These principles, applied to assess support needs of
adoptive families, include: giving the adoptive child a voice; developing collaborative working partnerships with adoptive families and relevant members of the child’s birth family; considering the impact of diversity and discrimination at all stages of the assessment process; using a range of approaches, including evidence-based approaches, rather than relying on one approach to ensure quality and reliability of the assessments and subsequent social support services; and taking an inter-agency approach to assessment and provision of services. The guide includes a series of charts of information gathered by use of evidence-based assessment tools to assess adoption support needs, including information gathered by observation, interview, or discussion for each dimension of the three domains within the framework. The use of standardized tools allows comparison of adoption support needs across different contexts (e.g., comparing a child’s needs in their birth family, with substitute carers, with a prospective adoptive family, and their needs once in placement). Social workers and other service providers are trained in use of these tools, including how to use them as a spring-board to open discussions during assessments.

In Canada, similar legislation and guidance includes the Children and Adoption Act of 2006, an Act of Parliament, and includes orders for children in family proceedings, adoptions with a foreign element, and enforcement guidance.

In the United States, the National Center for Adoption Law and Policy and Columbus (Ohio) Children’s Hospital created the “Adoption Academy”, a 12-week series that offers prospective adoptive parents a comprehensive educational program. The course, which is also simulcast via live video teleconferencing to audiences at locations distant from the capital city, provides an overview of the adoption process, the financial costs and social and emotional implications of adoption, cultural considerations, medical and behavioral aspects of adoption, how to prepare for adoption, and discussions with a panel of adoptees and adoptive parents. The international track includes information about government requirements and transcultural adoption considerations.

**Children Born and/or Separated from a Parent in Prison**

The rights of children who are born to women living in prison and of children and youth who are separated from a parent in prison are compromised by the legal status of their parent(s). The rights of prisoners have not been expanded to include the rights of children of prisoners in many countries, whereas the punishment of the adult extends to the child/youth whose needs are frequently not considered or met. Children born to prisoners who are citizens of countries within the European Union are allowed to remain with their mothers until the age of between nine months to three years old, depending on the country, impacting negatively on their early childhood development (EuroChips, 2007). According to some research, children of prisoners are “double victims”, forced to live apart from their parent(s) and also vulnerable to the stigma, social rejection, and shame associated with incarceration (Wolleswinkel, 2002). Each individual child’s situation is different, depending on the age and gender of the child and also which parent is living in prison. For instance, children of imprisoned mothers are often split up between different caretakers or left home alone, while children of imprisoned fathers usually live with their mothers but in impoverished circumstances. Additional problems, such as migration, parents who are addicted to drugs or alcohol, or parents who are violent or abusive, occur more often in the lives of children with imprisoned parent(s). The destabilizing effects of crime and the state’s response via criminal law severe the family, disrupting family life and bonds. The state’s legal responsibility to children in these circumstances is encapsulated in the Convention on the Rights of the Child (Articles 3, 9, 12), for instance Article 3(1) states: “In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities, or legislative bodes, the best interests of the child shall be a primary consideration”, in accordance with the age and maturity of the child. Within this framework, children should not be discriminated against on the
basis of the status of their parent(s), and states are to support parents in caring and providing for their children.

Most countries in Europe and elsewhere (e.g., Israel) assist pregnant prisoners with giving birth in a hospital setting outside of the prison. The Committee on the Prevention of Torture, based on a treaty among 40 European countries including the Federal Republic of Russia, Turkey, and Georgia, also states that: “Every effort should be made to meet the specific dietary needs of pregnant women prisoners, who should be offered a high protein diet, rich in fresh fruit and vegetables” (10th General Report on “Women Deprived of their Liberty”). This raises serious concerns about how to provide quality antenatal and postnatal care of imprisoned HIV-positive mothers and their infants (i.e., quality of care and support equal to that for non-imprisoned populations), given that many prison environments do not have provisions for babies and young children. Where babies and children are held in prison environments, their care should be supervised by trained social workers and child development specialists; children should have adequate opportunities for play, growth and development, and the opportunity to learn and explore outside of the prison confines. Care arrangements with family members and crèche-type facilities should be provided as childcare support and to provide opportunities for the child to interact with a number of adults and other children. Lasting care arrangements that maintain siblings and as much of the nuclear family together as possible are also critically important for children who are separated from imprisoned parent(s).

The relative importance of the mother-child attachment is the subject of much research and also cultural interpretation from country to country. In its 2000 summary report, The Council of Europe reported: “Prisons do not provide an appropriate environment for babies and young children, often causing long term developmental retardation. Yet, if babies and children are forcibly separated from their mothers they suffer permanent emotional and social damage. Most European prison systems provide some place for babies to stay with mothers but many hundreds of babies are nevertheless separated from their imprisoned mothers. This report argues that a new approach is needed for those few mothers of young children who commit serious offences and represent a danger to the community, and that the overwhelming majority of female offenders with young children should be managed in the community.”

A study in the UK among 12- to 18-year-old youth with a mother, father, sister, brother (including step- or half-relatives) in prison reported the following (selected) results relevant to care and support (Brown, 2001):

- The need for child- and youth-friendly visitations with member(s) of the family living in prison. First and subsequent visits with the incarcerated person are critical so that the youth can be assured of the mental and physical well being of the prisoner, since many arrests are traumatic or sudden/unexpected.
- The entire family is branded with stigma associated with having an imprisoned member. Prison staff needs to be trained in issues related to the impact of incarceration on the family.
- The damage of separation; continuity of relationships is very important. Youth reported high levels of distress to especially not be able to receive emotional support from their mothers (either imprisoned mothers or overstretched mothers caring for the family where the father is imprisoned). Such simple solutions as providing calling cards or covering transportation expenses can help improve access and communication with the person living in prison. Parent(s) in prison should receive counseling and parenting skills classes as part of their rehabilitation.
- The loss of income that is most usually associated with fathers being imprisoned severely restricts youth from social, educational, and other opportunities and further reinforces the sense of loss of a normal life.
- Resources are needed for young people coping with a family member in prison. Young people wanted a book of stories, a web site, and peer support groups where they could learn and support each other, and discuss issues related to the impact of having a family member in prison.
The European Action Research Committee on Children of Imprisoned Parents (EUROCHIPS), funded by the Bernard Van Leer Foundation, is an association of organizations and individuals related to children of imprisoned parent(s). Its European structure is working on contacts and projects in countries where there is limited awareness of the issue of children of imprisoned parents, or in which initiatives exist but in isolation from other national and international initiatives. EUROCHIPS seeks to act as a voice for prisoners’ children, to support exchange of ideas and good practice for children with imprisoned parents, to provide accurate information about types of needs and the number of children and young people impacted, and to train professionals on these subjects.

A study of the “explosion” of women among the prison population in California and of 19 community models for (low level, nonviolent, substance-using) women prisoners was conducted by Barbara Bloom and the National Council on Crime and Delinquency (NCCD) in 2006 to inform system reform. These findings and recommendations underlie a shift from punishment-based confinement models to community-based settings that can emphasize treatment, service provision, good parenting, vocational training, and community re-entry (Wolf, 2006):

- Embrace a gender-responsive model of community correction.
- Include a gender-responsive, structured risk assessment to identify candidates for community placement.
- Keep community correction facilities secure and small.
- Provide intensive services such as housing, job training and placement, parenting, education, substance abuse treatment, and physical and mental health care.
- Programming should be flexible, including individualized treatment plans and coordinated case management.
- Incorporate a process and outcome evaluation component into program planning, implementation, and a long-term follow up of women and their children.
- Include a comprehensive cost-benefit analysis of community corrections and prisons.
- Conduct a public awareness campaign to encourage community ownership of programming for female offenders.
- Assess the needs and available resources of the broader community and enhance and mobilize community-based services accordingly.
- Provide gender-responsive, trauma-sensitive reentry services and health care.
- Provide intensive training and technical assistance to program providers and security staff on gender-responsive strategies.
- Provide technical assistance to contractors on issues such as facility requirements, licensing, and security.
- Include enhanced community corrections as part of a larger reform effort that addresses sentencing policy, prevention and reentry programs, and intervention with children of incarcerated women.
IV. Management and Administration Related to Social Services

In order to accommodate children and families entering a system of care and support from many intake points and then accessing a wide variety of services and support, programs need to be both integrated and decentralized. Care is coordinated in order that a child or youth’s needs are individually assessed and met in the most efficient and effective way possible, with the best use of (usually limited) resources and the application of evidence-based interventions, services, and support. A number of critical minimum activities or tasks are necessary (modified from the Quality Assurance Project, 2007):

- Conduct service mapping and resource allocation and flow (to determine the extent of current service provision, gaps, and flow of human, technical, and financial resources to the child and family at the community level).
- Support task forces (at different levels, including community) to function in coordinative roles.
- Develop and implement action plans for children and youth (which require identification of the subsets of children in need within a population, assessment of the prevalence and types of needs, and prioritization from among a number of possibly competing objectives and actions).
- Develop a system for individual child/youth assessment and case management in order to ensure that the child and his/her family are getting needs met and that progress is achieved. This system should explicitly include children and youth in innovation and problem solving during their own “cases” and in order to improve service delivery across the system.
- Continuously disseminate information about the coordination of care and support to and among communities, families, and children to reinforce an environment of transparent and available services. This should include development of wall charts, pocket guides, and other tools to help disseminate standards of care and points of entry and linkage between services.
- Provide regular, supportive supervision and monitoring of staff and volunteers providing services and support.

Coordinating/managing referral networks, including HIV service organizations and PLHIV groups

A significant part of service and support provision is communication and coordination among a network of allied service providers (including HIV service organizations, support groups for parents living with HIV, support groups for youth in HIV-affected families, medical, mental health, substance use, social service and support agencies) in order to meet the needs and provide specific interventions for families and children living with HIV. Many countries have found it imperative to coordinate with a variety of service providers and establish/maintain multiple reciprocal service agreements in order to meet diverse client needs. Referrals to other programs (such as programs better able to serve children or youth) optimally occur within two weeks of determination of the appropriate level of care. Clients are enrolled in services based on client consent forms, confidentiality and other forms, naming and only authorizing the release of HIV confidential information to service providers when needed, naming who will receive the information and the date the authorization will expire (normally authorizing release and consent forms are only applicable for one year). The referring agency also establishes a system for verifying and monitoring placements to other service agencies to ensure that the placement(s) are appropriate, and that the client is receiving quality service that contributes to progress within the overall care plan. The range of needs for families living with HIV are enormous and can include the need for: nutritional support, financial resources and entitlements, parenting classes and support, legal assistance, housing, transportation, OB/GYN services including prenatal care during pregnancy, psychosocial support, dental and vision care, parenting needs, partner notification needs, support concerning HIV disclosure issues, treatment due to HIV disease progression, alcohol/drug use associated treatment and support, mental health support, disability or other special needs, prevention or treatment issues associated with exposure to tuberculosis or sexually transmitted infections, domestic violence interventions, crisis planning, etc.
The policies and procedures established by agencies should set standards for the content of care plans, including points for review and approval by supervisors. The combined program elements of policies and procedures, written case-specific documentation that includes a care/service plan and progress notes in each client’s chart, and active case monitoring comprise a system of checks and balances. This system helps to ensure provision of comprehensive services, careful monitoring of barriers to progress, client satisfaction with different referred services and providers, advancing client outcomes, and to also ensure full knowledge, motivation, and participation by clients during their care and support. Service plans are usually developed and negotiated directly with clients and a copy of the service plan is offered to each client to help reinforce that each service and support provider is in partnership with each family member or child.

Each service agency is responsible for maintaining a chart with progress notes (and specific actions for follow up) for each client; progress is documented, including contacts through other service and support providers. Most effective case coordination includes frequent communication and updates among the circle of key parties around a client, including frequently a diverse group of service providers. Family members may be significant partners in a client’s service plan, accepting responsibility for certain agreed upon activities, including help with accessing treatment, or support, or other services. Periodic reassessment of each case is most effectively accomplished via case conferences that include the family, child, and key service and support providers in order to reevaluate the service plan.

Each client maintains a right to privacy and confidentiality in contact with each service provider. Client consent must be obtained and documented at the point of consultation with each service and support provider. These records and documentation must be secured against unauthorized access, usually kept in locked files. Standards for confidentiality of HIV-related information is protected by public law and must be adhered to in order to properly establish client record/chart systems and referral systems.

When clients are lost to follow up, the best care and support providers have policies including home visits, written/electronic correspondence, and/or telephone calls to determine the client’s status and whether services should be terminated, other needs exist requiring a new service plan, or whether the client may need to seek the services of other providers. In the case of the latter, agencies will obtain written releases from clients in order to be able to share pertinent information with the new service provider.

In addition to universal standards of care, many agencies (e.g., Boston AIDS Consortium) specify additional standards for certain services. These might include client advocacy, day care, drop-in centers (to access peer support, social and recreational activities in order to overcome stigma and reduction), emergency assistance (to meet emergency needs for food, housing, transportation, and medication), foster care and adoption, peer support, volunteer support (to provide individual companionship and psychosocial support for families affected by HIV/AIDS), and other services. Programs providing child placement services have delineated policies to guarantee child protection, parental access, and custody-related or legal issues. The agencies are required to comply with state regulations, including licensing requirements, and must follow all state and federal guidelines for licensing and renewal of staff and for licensing prospective foster or adoptive parents. Standards for pediatric day care programs providing services to children with HIV, the siblings of children with HIV, and children of a parent or caregiver with HIV ensure that parents’ capacity to advocate for the child’s needs are enhanced, involving parents in the assessment, service planning, and decision making for the care of their child/children. They provide services to children and families in a way that promotes parental choice, assists the family in coping with multiple stresses related to caring for children infected/affected, and supports family autonomy. Standards stipulate that day care programs must have the capacity to provide the level of medical management needed to maintain the health, safety, and well being of children infected/affected with HIV/AIDS who are enrolled at the facility. Special provisions
include modifying the curriculum and activities; have resting space available; special feeding techniques and special dietary requirements; meeting special learning, emotional, and behavioral needs; accommodating neurological or developmental impairments; and other adaptive devices.

**Coordinating and managing staff**

Case management, direct service provision, and support assistance depend on quality program and staff capacity. Program capacity is evaluated across the needs of the intended beneficiaries, including the program’s service level and staff qualifications, so that caseload capacity can be assured. Structured training programs are needed to develop the professional skills and team skills of multidisciplinary teams that can meet the diverse cultural, developmental, interpersonal, and linguistic needs of clients of different ages and genders. Most effective programs maintain a system of up to date personnel files in order to assure that proper staff ratios are provided for the caseload, that staffing is gender-balanced (so that, for instance, female clients can be paired with female service providers and counselors if this increases the clients’ comfort levels), that staff patterns are matched to the communities they serve, and that staff performance is tracked and rewarded.

Qualified staff should be responsible for staff supervision and the type and frequency of supervisory activities, including evaluation of staff job performance, should be delineated. Some public agencies (for instance, the Boston Public Health Commission) stipulate the minimum standards (number of hours per month) for adequate supervision. Administrative supervision addresses issues related to overall operation of a program/agency and quality assurance, including staffing, policy, client documentation, financial administration, scheduling, and training. Periodic performance monitoring should be documented to ensure that staff are meeting quality service standards on an ongoing basis and to identify skill areas that might benefit from additional professional training. Because of the level of care and demand that might be expected of staff that are providing and/or coordinating a myriad of services and support to families and children affected by HIV, supervision also addresses issues related to direct client care and job-related stress (e.g., coping with crisis, preventing burnout, and maintaining appropriate client-staff boundaries). Most effective programs provide two sets of supervisors for staff, i.e., one who will monitor performance and one who will provide on-the-job training and support.

Each agency should maintain a staff training plan, including a description of how staff will be oriented and trained, required training topics, frequency of training, and types of on-the-job training provided. There should be a documented process for assessing ongoing staff training needs, attainment of progressive skill levels, and training records that document quality of training. Ongoing skills training might encompass the functions of intake, assessment and re-assessment, service planning, case coordination, case conferencing, couples and family counseling, crisis intervention, and monitoring/follow-up of services provided and referred. In order to ensure effective delivery of services to families and children affected by HIV, ongoing training must include sensitivity and ethics training, and annual confidentiality training, with an attestation signed by each staff person agreeing to abide by confidentiality requirements (AIDS Institute, 2006). Such training reinforces a service environment that is respectful, non-judgmental, supportive, affirming and humane. Recognizing that an inherent power differential exists between a service provider and a client, staff is helped to create a service environment where interaction is more equal. Concern and respect underlie an approach that meets uniform standards while also treating individual families and children and their unique needs, rather than perceiving them as homogenous members of a group or class. Training is an ongoing process that builds cultural and linguistic competence over time, including the ability of staff to acknowledge the limits of their competence and respond constructively during service interactions.

**Systems Strengthening and Monitoring**
The establishment of community-based social service systems evolved very slowly during the 1990s in Central and Eastern Europe and the former Soviet Union (Tobis, 2000). Romania is one of the few countries that passed legislation creating a national social service system. Lithuania also passed national legislation authorizing localities to deliver community-based services to vulnerable groups, but inadequate funding has limited scale up. Hungary’s extensive family support network of family help centers and parent advisory centers is funded directly by municipalities.

Illustrative Case Study: Massive changes in social policy in Romania led to deinstitutionalization of an estimated 100,000 children who had been living in orphanages prior to Romania joining the European Union. Many of these children who were resettled in birth families, foster families, and group homes have special needs resulting from early deprivation and institutionalization, including: aggressive behavior, inattention, hyperactivity, and disturbed attachment, among other dramatic emotional, behavioral, and cognitive development problems leading to attention deficit disorder, anxiety, learning and other disorders. The approach used in Romania was a combination of public policy and establishment of a child development infrastructure via collaboration by clinical and scientific leaders from the Bucharest Early Intervention Project (BEIP) and the country’s most notable child health and welfare NGO, SERA Romania. An Institute for Child Development (ICD) was established to coordinate the research, training, clinical services, and dissemination needed to create a modern child welfare system that can meet the needs of Romania’s most vulnerable children. The ICD is based on the Developmental Medicine Center (DMC) at Harvard-affiliated Children’s Hospital Boston, which has pioneered a model of integrated and collaborative clinical services, research, and training designed to provide better diagnoses, treatments, and, ultimately, cures. The ICD is building the local infrastructure and critical mass of local expertise necessary to respond to the changing needs of the child population; it will serve as a model of excellence for other nations.

Practical Implications: Some of the key innovations of the ICD can inform further strengthening of the child and family social service and welfare system in the Ukraine:

- To enable accurate identification of developmental problems, child psychology and other development assessment tools already available from other countries are being exported, translated, and pilot tested in Romania. ICD is building the capacity of local research investigators to implement model research and case management projects.
- ICD conducts child development seminars which have been incorporated into continuing professional education that is recognized by the Romanian Ministry of Labor.
- After renovating a clinical center, ICD received clinical certification from the Sector 1 Department of Child Protection. Clinical services include: general pediatrics, child psychiatry, child psychology, physical therapy, speech therapy, audiology, and electrophysiology, among others. The clinic will be organized according to the “hub and spoke” model developed by the Children’s Hospital/Harvard DMC. Patients will be evaluated, and then referred to one of a series of specialty services within the clinic (the “spokes”). The emphasis will be on expert diagnosis, treatment, and family support.
- ICD is conducting a national needs assessment in order to gauge the magnitude of different types of child vulnerabilities, including children with developmental disorders, handicaps, or genetic syndromes. This will enable ICD to better plan clinical services and recruit child health professionals as well as to inform policymakers making decisions about Romania’s child health services.
- A range of specialty services will address the multiple problems, both physical and psychological, deinstitutionalized and other special-needs children face. The clinics will be staffed by
multidisciplinary teams consisting of psychiatrists, psychologists, pediatricians, pediatric nurse practitioners, and other specialists who will provide clinical care and family support.

- The ICD organized a social work team to provide case management services, including development of a database of information and referral resources throughout the country. Case managers at the clinic will communicate with and support families before, during, and after their child’s diagnosis.
- A Romanian-language web-based information portal and a special help hotline will facilitate access by parents to information related to disabilities, development, and general health. Educational materials on child development will be available, as will special courses and support groups for biological, adoptive, and foster parents of post-institutionalized children and children with disabilities.

The evolution and progress of a system of child care responses should undergo continual evaluation and quality improvement. Monitoring is usually accomplished via a combination of evaluating compliance to a set of child care standards and regulations, licensing and accreditation reviews, and maintaining data bases to track the well being and protection of children enrolled in the system.

To support national monitoring efforts, UNAIDS has issued a revised set of core indicators and accompanying guidelines to assist countries in reporting on the status of the HIV epidemic and progress on the response (UNAIDS, 2007). One of these core indicators focuses on support for children affected by HIV and AIDS, i.e., “The percentage of orphaned and vulnerable children aged 0–17 whose households received free basic external support in caring for the child” (pgs. 44–45). This data is to be collected every 4–5 years through population-based surveys; heads of household are asked the following four questions about type and frequency of support received for each orphan and vulnerable child:

- Has this household received medical support, including medical care supplies, within the last 12 months?
- Has this household received school-related assistance, including school fees, within the last 12 months? (only asked of children 5–17 years-old)
- Has this household received emotional/psychological support, including counseling from a trained counselor and/or emotional/spiritual support or companionship within the last 3 months?
- Has this household received other social support, including socioeconomic support (e.g., clothing, extra food, financial support, shelter) and/or instrumental support (e.g., help with household work, training for caregivers, childcare, legal services) within the last three months?

Additional questions could be added to monitor other expressed needs of families caring for children with HIV, orphans, or other vulnerable children.

This paper provides highlights of lessons gleaned from review of a selection of current social support practices for families and children living with HIV. The selected practices are drawn primarily from developed country settings with abundant resources and well-organized public social service delivery systems.

These lessons are meant to inform the Government of the Ukraine as it embarks on policy and programmatic reform in order to build a more unified, coordinated, comprehensive national approach that is responsive to the varied needs of families and children living with HIV. This document is not meant to be prescriptive but rather to present lessons learned from selected family-based and child care programs, recognizing that what is appropriate for one country in terms of caring for HIV-affected parents and children will differ from another, based on different contexts, resources, and different cultural norms regarding
childhood, parenting, family care, childcare, and child protection. The intent is to provide guidance to assist the Government of Ukraine in adopting standards of social services delivery for: a) HIV-positive children, HIV parent(s), and their families, and b) other children affected by HIV without families who may be in need of foster care, adoption, or other care arrangements.

Highlights of lessons learned include the following:

- International child-rights principles and consensus among global experts proffer that it is in the “best interest” of the child to provide family-centered and family-based programming for children affected and/or infected with HIV, if at all possible. Long-term care that affords the security of family or family-like relationships, clear lines of responsibility, full access to a wide range of support services (including financial support), and legal permanence is preferable.

- Programming for social services is predicated on a holistic approach addressing the needs of the child or youth, parents or guardians, and other family members interacting and mutually supporting one another within a “family system.” Every effort should be made to support a family to stay intact; to support at risk mothers, to prevent HIV infection and provide long-term antiretroviral, substance abuse, TB, and other treatment and prophylaxis for adults/parents living with HIV (in order to prevent orphans); and to economically and emotionally stabilize families with members who may be incarcerated, in treatment, rehabilitation, or enduring other separations that can negatively effect children, particularly when combined with the social isolation and stigma that often accompanies HIV. Many national child protection acts are being amended to stipulate that institutional care of children should be provided only as a last resort.

It is widely acknowledged that it is a significant institutional challenge to create a linked, multisectoral and multilevel system of social and other services in order to meet the different age- and developmental-specific needs of children and their families variously affected by HIV. Most effective integrated systems approaches maximize partnerships between public service delivery and non-government, particularly community-based organizations, and between formal systems of care and support and informal systems, such as peer support groups among people living with HIV. Interlaced within generalized formal and informal, government and non-government services are approaches tailored to meet the specific needs of children and families living with the medical and social impacts of HIV and concurrent disabilities. National child- and youth-focused strategies include specific standards to assure access to appropriate services for these children and their families.

In a number of countries with integrated systems for care and support of children, social service departments and health departments work closely together to systematically analyze, understand, and track progress of children and young people within their families and the wider context in which they live. Social services play a pivotal role in providing counseling; addressing stigma associated with HIV; imprisonment; disability and other conditions; supporting adherence to treatment; and referring children and families in need of prophylactic or comprehensive treatment.

The concepts of providing both a high quality “comprehensive package of services” and an integrated, well-coordinated “continuum of care” suggest the need to institute flexible approaches that allow for the changing and multiple needs of each individual child to be met. These approaches are uniformly based on the following four practices:

- **ongoing, comprehensive needs analysis and regular progress monitoring** – of children/young people and adults and other family members living with HIV;
• an interdisciplinary approach with teams of educators, social workers, and health workers providing focused clinical and psychosocial “shared care” to the same child and/or family client;
• case management practices and standards that define minimum agency service requirements and that ensure uniformity and continuity of care as clients’ circumstances change over time and stage of HIV illness; and
• meaningful participation of children throughout the care and support approach. Children and young people are increasingly directly involved in decisions, policies, and improvements in service delivery that affect their own care and lives.

A number of countries with previously large numbers of individual children living in residential care facilities are undergoing policy and programmatic shifts to ensure that children are either returned to their families or receive care and support within family-based care models. Deinstitutionalization of children is widely being undertaken in order to reduce discrimination linked with institutionalization, to promote optimal growth and development, and to provide the most cost-effective care, support, and nurturance in family-like settings.

Disclosure of HIV status is an individual (child or parent) and family concern and decision that pivots on a combination of privacy issues, health care and social service needs, and the negative effects of stigma. One of the conceptual pillars for ensuring child protection while providing social services support is broad enforcement of public health laws that uphold confidentiality and informed consent procedures for disclosure of HIV status or HIV-related information among health insurance plans, health care information clearinghouses, and any health care or social services provider who transmits health information in written or electronic form. Another protective pillar is individual authorization through informed, written consent. A third protective pillar is provided through local child centers and hubs that can serve as networks to implement national child rights protection laws in a manner that is responsive to each local condition, reaching especially poor, marginalized, and other vulnerable children such as children in conflict with the law and street children; and children and their families affected by HIV, substance use, tuberculosis, and other intersecting issues.

Effectively and efficiently coordinating and managing multiple services reaching individual children and families living with HIV require the best use of (usually limited) resources and the application of evidence-based interventions, services, and support. Key elements to address complex management demands include:

• Policies that provide equal opportunity and access to child welfare and child protection services by all, including children and families living with HIV.
• Well trained multidisciplinary teams providing services by following coordinated care plans that attain high quality standards through continuous assessment, tracking, and quality improvement programs. This requires continual performance- and ethics- based staff training; adjustment of appropriate staff ratios to case loads; a proactive system for ensuring confidentiality; and adequate, supportive, and corrective supervision.
• Well designed communication and referral networks, based on multiple and reciprocal service agreements that include HIV service organizations and support groups of people living with HIV.
• A system of monitoring that incorporates international standards and indicators.

These lessons and subsequent discussions among ministry partners of the Ukraine support the following major recommendations and practical implications:
Annexes

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Annex A: U.S. Core Indicators and Standards of Quality Child Care

Annex B: Overview of Child Development and the Need for Parental Support

Annex C: UNAIDS Core Indicators for Monitoring the Declaration of Commitment on HIV/AIDS – 2008 Reporting

Annex D: Authorization to Release HIV-Related Information

Annex E: Child Bereavement Network Guidelines for Health and Social Workers
The following summary of core indicators and standards are excerpted from a research update, prepared by Pennsylvania State University and the National Resource Center for Health and Safety in Child Care at the University of Colorado for the Office of the Assistant Secretary for Planning and Evaluation and Health Resources and Services Administration/Maternal and Child Health Bureau of the U.S. Department of Health and Human Services (Feine, 2002).

1. The child abuse reporting and clearance indicator includes the following twelve standards:
   1) The facility shall report to the department of social services, child protective services, or police any instance where there is reasonable cause to believe that child abuse, neglect, or exploitation may have occurred.
   2) Caregivers and health professionals shall establish linkages with physicians, child psychiatrists, nurses, nurse practitioners, physicians’ assistants, and child protective services in order to provide them with consultation about suspicious injuries or other circumstances that may indicate abuse or neglect.
   3) Caregivers must be aware of the common behaviors shown by abused children and, if many such children are in the center, make special provisions for them by the addition of staff.
   4) Caregivers who report abuse in the settings where they work shall be immune from discharge, retaliation, or other disciplinary action for that reason alone.
   5) Employees and volunteers in centers shall receive an instruction sheet about child abuse reporting that contains a summary of the child abuse reporting statute and a statement that they will not be discharged solely because they have made a child abuse report.
   6) All caregivers in all settings and at all levels of employment shall know the definitions of the four forms of child abuse and shall know the child abuse reporting requirements.
   7) Caregivers with a year of experience in child care, and all small family home caregivers, shall know the symptoms and indicators that abused children may show. They shall know the common factors, both chronic and situational, that lead to abuse. These symptoms and indicators shall be listed in the written policies.
   8) Center directors shall know methods for reducing the risks of child abuse. They shall know how to recognize common symptoms and signs of child abuse.
   9) Caregivers shall have ways of taking breaks and finding relief at times of high stress (e.g., they shall be allowed 15 minutes of break time every 4 hours in addition to a lunch break of at least 30 minutes).
   10) The physical layout of the facilities shall be arranged so that all areas can be viewed by at least one other adult in addition to the caregiver at all times to reduce the likelihood of isolation or privacy for individual caregivers with children, especially in areas where children may be undressed or have their genitals exposed.
   11) Caregivers shall be knowledgeable about the symptoms and signs caused by sexually transmitted diseases in children. They must refer such children for care by calling the health care provider as well as the parent in order to be certain that the child is taken for care. They must determine from the health care provider when the child may return to the site and what precautions, if any, are needed to protect other children. Care giving training on these items shall be documented.
   12) Directors and large family home caregivers shall check references and examine employment history before employing any staff, including substitutes, who will be alone with a child or a group of children in child care.

2. The proper immunizations indicator has one standard, i.e., that the latest version of the Advisory Committee on Immunization Practices (ACIP) of the U.S. Public Health Service and the American Academy of Pediatrics (AAP) immunization schedule is followed.
3. Child to staff ratios and group sizes for centers and large family child care homes shall be maintained as follows during all hours of operation in order to ensure the health (prevention of widespread ear infections, hemophilus influenzas, etc.), safety, mental health, and school readiness of children:

<table>
<thead>
<tr>
<th>Age</th>
<th>Child-staff Ratios</th>
<th>Maximum Group Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth – 12 months</td>
<td>3:1</td>
<td>6</td>
</tr>
<tr>
<td>13 – 24 months</td>
<td>3:1</td>
<td>6</td>
</tr>
<tr>
<td>25 – 30 months</td>
<td>4:1</td>
<td>8</td>
</tr>
<tr>
<td>31 – 35 months</td>
<td>5:1</td>
<td>10</td>
</tr>
<tr>
<td>3 years old</td>
<td>7:1</td>
<td>14</td>
</tr>
<tr>
<td>4 years old</td>
<td>8:1</td>
<td>16</td>
</tr>
<tr>
<td>5 years old</td>
<td>8:1</td>
<td>16</td>
</tr>
<tr>
<td>6 – 8 years old</td>
<td>10:1</td>
<td>20</td>
</tr>
<tr>
<td>9 – 12 years old</td>
<td>12:1</td>
<td>24</td>
</tr>
</tbody>
</table>

4. The director and teacher qualifications indicator forms a continuum with staff training and therefore a rather arbitrary line distinguishes these. This indicator is comprised of the following (15) standards:

1) The director of a center enrolling fewer than 60 children shall be at least 21 years old and shall have an undergraduate degree in early childhood education, child development, social work, nursing, or other child related field, or a combination of college coursework and experience under qualified supervision. Experience must include 2 years as a teacher of children of the age group(s) in care.

2) The director of a center enrolling 60 or more children shall be at least at least 21 years old and shall have an undergraduate degree in early childhood education, child development, social work, nursing, or other child related field, or a combination of college coursework and experience under qualified supervision. Education shall include one course in administration, and 3 years’ experience as a teacher of children of the age group(s) in care.

3) Centers enrolling 30 or more children must employ a non-teaching director. Centers with fewer than 30 children may employ a director who teaches as well.

4) In addition to these credentials, a director of a center or a small family child care home system enrolling 30 or more children shall provide documentation of one course in health and safety issues for out of home facilities, in addition to other educational qualifications, upon employment. This training shall include at least the following content:
   - Mechanisms of communicable disease spread;
   - Procedures for preventing the spread of communicable disease, including hand washing, sanitation, diaper changing, health department notification of reportable disease, equipment, toy selection and proper washing, disinfecting to reduce disease and injury risk, and health related aspects of pets in the facility;
   - Immunization requirements for children and staff;
   - Common childhood illnesses and their management;
   - Organization of the facility to reduce illness and injury risks;
   - Training child care staff and children in infection and injury control;
   - Emergency procedures;
   - Promotion of health in the child care setting;

5) In addition to the general requirements in Qualifications of Directors of Centers, the director of a facility for children under 5 years of age shall have not less than 2 to 3 years of experience as a teacher of infants, toddlers, and preschoolers.

6) In addition to the general requirements in Qualifications of Directors of Centers, the director of a school-age child care facility shall hold an undergraduate degree in early childhood education, elementary
education, child development, recreation, or other child related field, and not less than 2 years' experience working with school-age children.

7) Directors and large family home caregivers shall check references and examine employment history before employing any staff, including substitutes, who will be alone with a child or a group of children in child care.

8) Caregivers shall have knowledge of child development and early childhood education; an undergraduate degree in early childhood education, child development, social work, nursing, or other child related field; and 1 year's experience and on the job training to provide a nurturing environment and to meet the child's out of home needs.

9) Centers shall employ licensed, certified teaching, care giving staff for direct work with children in a progression of roles such as the following: aides, assistant teachers, associate teachers, teachers, lead teachers, and; education coordinators.

10) Every center, regardless of setting, shall have at least one licensed/certified lead teacher (or mentor teacher) who has a Bachelor of Arts, Bachelor of Science, Bachelor of Education, or Master of Education degree in early childhood education, child development, social work, nursing, or other child-related field, in addition to at least 1 year of experience working in child care serving this age group. All teachers in charge of a group shall be licensed/certified as lead teachers, teachers, or associate teachers.

11) Caregivers shall want to work with infants and toddlers when asked and shall know what the job entails-fostering interaction, diapering, bathing, feeding, holding, comforting, and responding.

12) Every center, regardless of setting, shall have at least one licensed/certified lead teacher (or mentor teacher) who has a Bachelor of Arts, Bachelor of Science, Bachelor of Education, or Master of Education degree in early childhood education, child development, social work, nursing, or other child-related field, as well as at least 1 year of experience working in child care with this age group.

13) Caregivers shall demonstrate an ability to apply their understanding of the developmental characteristics of 3- to 5-year-olds. Caregivers shall demonstrate knowledge and understanding of these children's independence and social competence, more complex inner lives, and increasing ability to adapt to their environment and cope with stress.

14) Every center, regardless of setting, shall have at least one licensed/certified group leader (or mentor teacher) who has a Bachelor of Arts, Bachelor of Science, Bachelor of Education, or Master of Arts degree in child development or early childhood education covering ages newborn to 8 or 3 to 8, elementary education, recreation, or a related field, as well as at least 1 year of experience working in child care.

15) Caregivers shall demonstrate knowledge about the social and emotional needs and developmental tasks of 5- to 12-year-old children, and shall know how to implement a nonacademic, enriching program.

5. The staff training indicator (which overlaps with the previous indicator and is quite variable between states) is based on the following (12) standards:

1) Caregivers shall be educationally qualified in advance for the role they are entering and shall receive orientation training during the week immediately following employment. Caregivers shall also receive continuing education each year. In centers, directors shall ensure that 12 hours of staff meetings are held, in addition to the continuing education specified in Continuing Education.

2) All new full-and part-time staff shall be oriented to, and demonstrate knowledge of, the following:
   - The goals and philosophy of the facility.
   - The names, ages, and specific development needs of the children for whom the caregiver will be responsible.
   - Any special adaptation(s) of the facility required for a child with special needs.
   - Any special health or nutrition need(s) of the children assigned to the caregiver.
   - The planned program of activities at the facility.
   - Routines and transitions.
   - Acceptable methods of discipline.
- Policies of the facility relating to parents.
- Meal patterns and food-handling policies of the facility.
- Occupational health hazards for caregivers.
- Emergency health and safety procedures.
- General health policies and procedures, including but not limited to hand washing techniques; diapering technique and toileting; correct food preparation, serving, and storage techniques if employee prepares food; formula preparation, if formula is handled.
- Child abuse detection, prevention, and reporting.
- Teaching health promotion concepts to children and parents as part of the daily care provided to children.
- Recognizing symptoms of illness.

3) Orientation training in centers shall be documented. The director shall document the topics covered and the dates on which the orientation was provided.

4) During the first three months of employment, the center director or large family home caregiver shall document, for all full-time and part-time staff, additional orientation in and the employee's satisfactory knowledge of the following topics for the purpose of noting and responding to illness in the facility: recognition of symptoms of illness and correct documentation procedures for recording symptoms; exclusion and readmission procedures; cleaning, sanitation, and disinfection procedures; procedures for administering and documenting medications to children; procedures for notifying parents or legal guardians of communicable disease occurring in children or staff within the facility; procedures for performing daily child health assessments.

5) Staff members shall not be expected to take responsibility for any aspect of care for which they have not been oriented and trained.

6) The director of a center or a large family-child-care home shall ensure that all staff involved in the provision of direct care are certified in pediatric first aid (including rescue breathing and first aid for choking). At least one certified staff person shall be in attendance at all times.

7) Small family home caregivers should be certified in pediatric first aid training.

8) Pediatric first aid training, including rescue breathing and first aid for choking, shall be consistent with pediatric first aid training developed by the American Red Cross, the American Heart Association, or the National Safety Council for First Aid Training Institute. The offered first aid instruction shall include, but not be limited to the emergency management of: bleeding, burns, poisoning, choking, injuries (including insect, animal, and human bites), shock, convulsions or seizures, musculoskeletal injuries (sprains, fractures), dental emergencies, head injuries, allergic reactions, eye injuries, loss of consciousness, electric shock, drowning.

9) Facilities that have a swimming pool or built-in wading pool shall require infant and child CPR training for caregivers. At least one of the caregivers, volunteers, and other adults who are counted in the child: staff ratio for wading and swimming shall be trained in basic water safety and certified in infant and child CPR each year by a person certified as an instructor in water safety and in CPR. Written verification of CPR and lifesaving certification, water safety instructions, and emergency procedures shall be kept on file.

10) Facilities that serve children with special needs shall have at least one caregiver certified in infant and child CPR. Written verification of CPR certification shall be kept on file.

11) Directors and all caregivers shall have at least 30 clock hours per year of continuing education in the first year of employment, 16 clock hours of which shall be in child development programming and 14 of which shall be in child health, safety, and staff health; and 24 clock hours of continuing education based on individual competency needs each year thereafter, 16 of which shall be in child development programming and 8 of which shall be in child health, safety, and staff health.

12) The supervision/discipline indicator includes (8) standards that comprise general discipline and basic programming related to developmentally appropriate practices with children: Each facility's supervision policy shall specify:
- That no child shall be left alone or unsupervised while under the care of the child care staff. Caregivers shall supervise children at all times, even when the children are sleeping (a caregiver must be able to both see and hear infants while they are sleeping). Caregivers shall not be on one floor while children are on another floor. Schoolage children shall be permitted to participate in activities and visit friends off premises as approved by their parents and by the caregiver(s).
- That developmentally appropriate child: staff ratios shall be met during all hours of operating, including field trips. The policy shall include specific procedures governing supervision of the indoor and outdoor play spaces that describe the child: staff ratio, precautions to be followed for specific areas and equipment, and staff assignments for high-risk areas. The supervision policies of centers and large family-child-care homes shall be written policies.
- Facilities shall maintain supervision of children at all times.
- Discipline shall include positive guidance, redirection, and the setting of clear-cut limits that foster the child's ability to become self-disciplined. Disciplinary measures shall be clear, understandable, and consistent, and shall be explained to the child before and at the time of any disciplinary action.
- Caregivers shall guide the child to develop self-control and orderly conduct in his/her relationships with peers and adults. Caregivers shall show children positive alternatives rather than just telling children "no." Good behavior shall be rewarded.
- Caregivers shall intervene immediately when children become physically aggressive.
- Disciplinary practices established by the facility shall be designed to encourage the child to be fair, to respect property, and to assume personal responsibility and responsibility for others.
- The following behavior shall be prohibited in all child care settings and by all caregivers: corporal punishment, including hitting, spanking, beating, shaking, pinching, and other measures that produce physical pain; withdrawal or the threat of withdrawal of food, rest, or bathroom opportunities; abusive or profane language; any form of public or private humiliation, including threats of physical punishment; any form of emotional abuse, including rejecting, terrorizing, ignoring, isolating, or corrupting a child.
- Children shall not be physically restrained except as necessary to ensure their own safety or that of others, and then only for as long as is necessary for control of the situation. Children shall not be given medicines or drugs that will affect their behavior except as prescribed by their health care provider.
- "Time out" that enables the child to regain control of him/herself and that keeps the child in visual contact with a caregiver shall be used selectively, taking into account the child's developmental stage.

6. The fire drills indicator is based on the following (5) key standards:

1) The facility shall have a written plan for reporting and evacuating in case of fire, flood, tornado, earthquake, hurricane, blizzard, power failure, or other disaster that could create structural damages to the facility or pose health hazards. Staff will be trained on this emergency plan.
2) Evacuation drills shall be practiced on a monthly basis in tornado season; every 6 months for earthquakes; and annually for hurricanes.
3) The center director shall use a daily class roster (and head count) in checking the evacuation and return to a safe indoor space of all children in attendance during an evacuation drill.
4) A fire evacuation procedure shall be approved by a fire inspector and shall be practiced at least monthly from all exit locations at varied times of the day, including naptime.
5) A fire evacuation procedure shall be maintained by the caregiver and practiced at least monthly from all exit locations at varied times of the day, including naptime.

7. The indicator for administration of medication is based on (5) standards:

1) The administration of medicines at the facility shall be limited to: those prescribed medications ordered and those nonprescription medications recommended by a health care provider for a specific child; with written permission of the parent or legal guardian referencing a written or telephone instruction received by the facility from the health care provider.
2) Any prescribed or over-the-counter medication brought into the facility by the parent, legal guardian, or responsible relative of a child shall be dated, and shall be kept in the original container labeled by a pharmacist with the child's first and last names; the date the prescription was filled; the name of the health care provider who wrote the prescription (or made the recommendation); the medication's expiration date; and specific, legible instructions for administration, storage, and disposal (i.e., the manufacturer's instructions or prescription label).

3) All medications, refrigerated or unrefrigerated, shall have child protective caps, shall not be used beyond the expiration date, shall be stored away from food at the proper temperature, and shall be inaccessible to children.

4) There shall be a written policy for the use of any commonly used, nonprescription medication as specified in Medication Policy.

5) Any caregiver who administers medication shall be trained to check for the name of the child, to read the label/prescription directions in relation to the measured dose, frequency, and other circumstances relative to administration (e.g., relation to meals); and to document administration.

8. The indicator concerning emergency plan/contacts has one standard. The facility shall have a written plan for reporting and managing any incident or unusual occurrence that is threatening to the health, safety, or welfare of the children or staff. The facility shall also include procedures for staff training on this emergency plan. The following incidents, at a minimum, shall be addressed in the emergency plan: a) lost or missing child; b) sexual or physical abuse or neglect of a child; c) injuries requiring medical or dental care; d) serious illness requiring hospitalization (or death) of a child enrolled in the facility, or death of a caregiver, including deaths that occur outside of child care hours. The following procedures, at a minimum, shall be addressed in the emergency plan: provision for a caregiver to accompany a child to emergency care and remain with the child until the parent or legal guardian assumes responsibility for the child; the source of emergency medical care—a hospital emergency room, clinic, or other constantly staffed facility known to caregivers and acceptable to parents; that first aid kits are resupplied following each first aid incident; and the names and addresses of a least three licensed providers of dental services who have agreed to give emergency advice and/or accept emergency dental referrals of children.

9. The following standards related to outdoor playground safety are a selection:

- The outdoor play area shall be enclosed with a fence or natural barriers. The barrier shall be at least 4 feet in height and the bottom edge shall be no more than 3 1/2 inches off the ground. There shall be at least two exits from such areas. Gates shall be equipped with self-closing and positive self-latching closure mechanisms. The latch or securing device shall be high enough or of such a type that it cannot be opened by small children. The openings in the fence shall be no greater than 3 1/2 inches.
- The soil in play areas shall not contain hazardous levels of any toxic chemical or substances, including lead content. Lead in soil shall not exceed 500 parts per million (ppm). The facility shall have initial soil samples and analyses performed by the local health department, extension service, or environmental control testing laboratory, every 2 years where exteriors of buildings are painted with lead containing paint, and when there is good reason to believe a problem may exist.
- Anchored play equipment shall not be placed over, or immediately adjacent to, hard surfaces. Outdoor play equipment shall be of safe design and in good repair. Climbing equipment and swings shall be set in concrete footings located below ground surface (at least 6 inches). Swings shall have soft and, or flexible seats. Access to play equipment shall be limited to age groups for which the equipment is developmentally appropriate. All pieces of playground equipment shall be designed to match the body dimensions of children.
- All pieces of playground equipment shall be surrounded by a resilient surface (e.g., fine, loose sand; wood chips; wood mulch) of an acceptable depth (9 inches), or by rubber mats manufactured for such use, consistent with the guidelines of the Consumer Product Safety Commission and the standard of the American Society for Testing and Materials, extending beyond the external limits of the piece of equipment for at least 4 feet beyond the fall zone of the equipment. These resilient surfaces must conform to the standard stating that the impact from falling from the height of the structure will be less than or equal to peak deceleration. Organic materials that support colonization of molds and bacteria shall not be used.

- The maximum height of any piece of playground equipment shall be no greater than 5 and 1/2 feet if children up to the age of 6 are given access to it, and no higher than 3 feet if the maximum age of children is 3 years.

- All walking surfaces, such as walkways, ramps, and decks, shall have a non-slip finish.

- The center director and the large and small family home caregiver shall conduct inspections of the playground area and the playground as specified below. The general playground surfaces shall be checked every day for broken glass, trash, and other foreign materials (e.g., animal excrement). The playground area shall be checked on a daily basis for areas of poor drainage and accumulation of water and ice.

10. The indicator on inaccessibility of toxic substances is based on (a selection of) the following (14) standards:

1) Cleaning materials, detergents, aerosol cans, pesticides, health and beauty aids, poisons, and other toxic materials shall be stored in their original labeled containers and shall be used according to the manufacturer’s instructions and for the intended purpose. They shall be used only in a manner that will not contaminate play surfaces, food, or food preparation areas, and that will not constitute a hazard to the children. When not in actual use, such materials shall be kept in a place inaccessible to children and separate from stored medications and food.

2) The poison control center and or physician shall be called for advice about safe use of any toxic products (e.g., pesticides, plants, rat poison) or in any ingestion emergency and their advice shall be documented in the facility’s files.

3) Employers shall provide child care workers with hazard information, as required by the U.S. Occupational Safety and Health Administration (OSHA), about the presence of toxic substances such as asbestos or formaldehyde (including as ingredients of art materials and disinfectants).

4) When the manufacturer's Material Data Safety Sheet shows the presence of any toxic effects, these materials shall be replaced with nontoxic substitutes. If no substitute is available, the product shall be eliminated.

5) Radon concentrations shall be less than 4 picocuries per liter of air.

6) Any asbestos that is friable or in a dangerous condition found within a facility shall be removed by a contractor certified to remove asbestos, encapsulated, or enclosed in accordance with existing regulations of the (U.S.) Environmental Protection Agency. Nonfriable asbestos shall be identified to prevent disturbance and or exposure during remodeling or future activities.
7) Pipe and boiler insulation shall be sampled and examined in an accredited laboratory for the presence of asbestos in a friable or potentially dangerous condition.

8) Chemicals used in lawn care treatments shall be limited to those listed as nonrestricted use. All chemicals used inside or outside shall be stored in their original containers in a safe and secure manner.

9) All arts and crafts materials used in the facility shall be nontoxic. There shall be no eating or drinking by children or staff during use of such materials.

10) Poisonous or potentially harmful plants on the premises shall be inaccessible to children. All plants accessible to children shall be identified and checked by name with the local poison control center to determine safe use.

11) Carpets made of nylon, orlon, wool and/or silk, and other materials that emit highly toxic fumes when they burn shall not be used.

12) Insulation or other materials that contain elements that may emit toxic substances (e.g., formaldehyde) over recommended levels in the child care environment shall not be used in facilities.

13) Any surface painted before 1978 shall be tested for excessive lead levels.

- In all centers, both exterior and interior surfaces covered by paint with lead levels of 0.06 percent and above and accessible to children shall be removed by a safe chemical or physical means or made inaccessible to children and refinished with lead-free paint or nontoxic material.
- In large and small family child care homes, flaking or deteriorating lead based paint on interior or exterior surfaces, equipment, or toys accessible to preschool age children shall be removed or abated according to health department regulations.

14) Construction, remodeling, or alterations of structures during child care operations shall be done in such a manner as to prevent hazards or unsafe conditions (e.g., fumes, dust, safety hazards).

11. There are (8) major standards informing the indicator for hygienic hand washing and diapering:

1) Staff and children shall wash their hands (washing and scrubbing for at least 10 seconds with soap and warm running water) at least at the following times, and whenever hands are contaminated with body fluids: before food preparation, handling, or serving; after toileting or changing diapers; after assisting a child with toilet use; before handling food; before any food service activity (including setting the table); before and after eating meals or snacks; after handling pets or other animals.

2) Toilets and sinks, easily accessible for use and supervision, shall be provided in the following ratios: toilets, urinals, and hand sinks shall be apportioned at a ratio of 1:10 for toddlers and preschool-age children and 1:15 for school-age children. Maximum toilet height shall be 11 inches and maximum hand sink height shall be 22 inches. Urinals shall not exceed 30 percent of the total required toilet fixtures. When the number of children in the ratio is exceeded by one, an additional fixture shall be required. These numbers shall be subject to the following minimums:
• A minimum of one sink and one flush toilet for 10 or fewer toddlers and pre-school age children using toilets.
• A minimum of one sink and one flush toilet for 15 or fewer school age children using toilets.
• A minimum of two sinks and two flush toilets for 16 to 30 children using toilets.
• A minimum of one sink and one flush toilet for each additional 15 children.

3) The changing area shall never be located in food preparation areas and shall never be used for temporary placement or serving of food. Changing tables shall have impervious, nonabsorbent surfaces. Safety straps on changing tables shall not be used.

4) If cloth diapers are used, a toilet shall be easily accessible so that waste contents may be disposed of by dumping before placing the diapers in the waste receptacle. Conveniently located, washable, plastic lined, tightly covered receptacles, operated by a foot pedal, and shall be provided for soiled burping cloths and linen.
Annex B: Overview of Child Development and the Need for Parental Support

While each child is unique, there are also enough similarities to group as general, sequential growth and development milestones spanning physical, emotional, intellectual/mental acuity, and other social and behavioral aspects of a child’s life. The following table provides an overview of “average” child development from infant through 5 years of age. It is important to keep in mind that the time frames presented are averages and some children may achieve various developmental milestones earlier or later than the average but still be within range.

<table>
<thead>
<tr>
<th>Physical and Language</th>
<th>Emotional</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Birth to 1 month:</strong></td>
<td>Generalized Tension</td>
<td>Helpless</td>
</tr>
<tr>
<td>Feedings: 5-8 per day</td>
<td>Helpless</td>
<td>Asocial</td>
</tr>
<tr>
<td>Sleep: 20 hrs per day</td>
<td>Helpless</td>
<td>Fed by mother</td>
</tr>
<tr>
<td>Sensory Capacities: makes basic distinctions in vision, hearing, smelling, tasting, touch, temperature, and pain perception</td>
<td>Helpless</td>
<td>Fed by mother</td>
</tr>
<tr>
<td><strong>2 to 3 months</strong></td>
<td>Delight</td>
<td>Visually fixates at a face, smiles at a face, may be soothed by rocking.</td>
</tr>
<tr>
<td>Sensory Capacities: color, perception, visual exploration, oral exploration. Sounds: cries, coos, grunts</td>
<td>Delight</td>
<td>Visually fixates at a face, smiles at a face, may be soothed by rocking.</td>
</tr>
<tr>
<td>Motor Ability: control of eye muscles, lifts head when on stomach.</td>
<td>Delight</td>
<td>Visually fixates at a face, smiles at a face, may be soothed by rocking.</td>
</tr>
<tr>
<td><strong>4 to 6 months</strong></td>
<td>Enjoys being cuddled</td>
<td>Recognizes his/her mother. Distinguishes between familiar persons and strangers, no longer smiles indiscriminately. Expects feeding, dressing, and bathing.</td>
</tr>
<tr>
<td>Sensory Capacities: localizes sounds Sounds: babbling, makes most vowels and about half of the consonants Feedings: 3-5 per day Motor Ability: control of head and arm movements, purposive grasping, rolls over.</td>
<td>Enjoys being cuddled</td>
<td>Recognizes his/her mother. Distinguishes between familiar persons and strangers, no longer smiles indiscriminately. Expects feeding, dressing, and bathing.</td>
</tr>
<tr>
<td><strong>7 to 9 months</strong></td>
<td>Specific emotional attachment to mother. Protests separation from mother.</td>
<td>Enjoys &quot;peek-a-boo&quot;</td>
</tr>
<tr>
<td>Motor Ability: control of trunk and hands, sits without support, crawls.</td>
<td>Specific emotional attachment to mother. Protests separation from mother.</td>
<td>Enjoys &quot;peek-a-boo&quot;</td>
</tr>
<tr>
<td><strong>10 to 12 months</strong></td>
<td>Anger</td>
<td>Responsive to own name. Wave bye-bye. Plays pat-a-cake, understands &quot;no-no!&quot;</td>
</tr>
<tr>
<td>Motor Ability: control of legs and feet, stands, creeps, apposition of thumb and fore-finger. Language: says one or two words, imitates sounds, and responds to simple commands. Feedings: 3 meals, 2 snacks Sleep: 12 hours, 2 naps</td>
<td>Anger</td>
<td>Responsive to own name. Wave bye-bye. Plays pat-a-cake, understands &quot;no-no!&quot;</td>
</tr>
<tr>
<td></td>
<td>Affection</td>
<td>Gives and takes objects.</td>
</tr>
<tr>
<td></td>
<td>Fear of strangers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Curiosity, exploration</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Parents, pediatricians, and other children, social, and support providers are all instrumental in forming a circle of care around each child. As children grow and develop, parents also progress through definite stages of development as their roles change. Parents will pass through five stages of emotional growth and development, each stage reflecting the problems they encounter as their youngster moves from one developmental stage to another. The five stages of parental development are outlined below (Alma Friedman, MD and David Friedman, MD):

<table>
<thead>
<tr>
<th>Stage of Child Development</th>
<th>Parent's Task</th>
<th>Stage of Parent Development</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant</td>
<td>To find out what your new baby is trying to tell you.</td>
<td>The parent learns the baby's cues and gains the infant's trust and confidence. Many parents become frustrated by their inability to tell what their baby wants.</td>
</tr>
<tr>
<td>Toddler</td>
<td>To accept some loss of control while</td>
<td>Parents must learn to accept the growth of their child. Many parents, who just &quot;love babies,&quot; find...</td>
</tr>
<tr>
<td>Age Group</td>
<td>Description</td>
<td>Behavior/Caregiver Expectation</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------</td>
<td>--------------------------------</td>
</tr>
<tr>
<td>Preschooler</td>
<td>To allow their child to assert themselves and show initiative while modeling sensible limits.</td>
<td>Parents must learn to emotionally separate from their child by setting limits on their youngster's actions but not their feelings. &quot;You have a right to get angry but you can not hit me.&quot;</td>
</tr>
<tr>
<td>School-age</td>
<td>To be there when needed without intruding unnecessarily and to have respect for the child's feelings</td>
<td>Parents must learn to accept their child's declaration of independence without feeling hurt, disappointed, or angry.</td>
</tr>
<tr>
<td>Teenager</td>
<td>To adjust to changing roles and relationships in the family as the teenager struggles to establish their own identity</td>
<td>Parents must learn to build a new life, having been thoroughly challenged by one's teen. Parents must be communicative and flexible and not treat the teenager as if they were still a child.</td>
</tr>
</tbody>
</table>

Parents and grandparents, other caregivers, and other family members, neighbors, and community members have a tremendous influence over the well-being of a child, beyond meeting their basic survival needs. This sphere of influence is enormous and includes the following aspects that also contribute to a child eventually becoming an adult who can fully relate and contribute within society:

- Loving, nurturing and bonding with children,
- Providing emotional interaction and connection important to brain development,
- Being creative and engaging in play and exploration with children,
- Setting ground rules for appropriate behavior and discipline,
- Encouraging social skills and play with others,
- Helping children feel important and develop healthy self-esteem,
- Providing a learning environment and positively reinforcing the child’s ability to learn,
- Gradually incorporating healthy and nourishing foods as the child’s diet expands beyond breast milk (after 4 – 6 months of age),
- Establishing routine eating and sleeping habits,
- Wisely choosing the type of group or individual child care that matches the needs of a child.

Childhood is the most critical stage of human development, leading to health, personality and behavioral development, the capacity for psychosocial and cognitive growth, intelligence, etc. Yet the complex development milestones listed above can be adversely impacted by a range of childhood and adolescent disorders, including attention deficit disorder, autism and/or Asperger’s syndrome, bedwetting in children over 4 years of age, different degrees of mental retardation, learning disabilities such as dyslexia, neurological disorders such as Tourette’s syndrome, physical disabilities, manic-depressive illnesses, obsessive compulsive disorders, and problems with language, speech, and/or hearing (communication disorders). Major illnesses such as hepatitis B, hepatitis C, and HIV can impact both a child’s development and subsequent needs for care and support from family and other caregivers.
The course of HIV infection in infants and children is different to that in adults, and it is important that their monitoring, care and treatment is provided by doctors, social workers, and other staff at a specialist clinic skilled in looking after young people with HIV. Long-term natural history studies of HIV disease progression rates among children point to the importance of ART availability. In an analysis of 170 vertically-infected children enrolled in the European Collaborative Study (Gray et al., 2001), more than 25% of HIV-infected children born between 1985-1988 (during which time there was no recommended treatment) progressed to AIDS or death by 1 year of age. In comparison, 15% of infants born between 1989-94 (during which time monotherapy for symptomatic infants was recommended) and 5% of infants born between 1995-9 (during which time combination therapy at early disease stages was recommended) progressed to AIDS or death by 1 year of age. Children born in resource-rich countries after 1997, with the introduction of HAART, are significantly less likely to progress than children born earlier and exposed to either mono, or no therapy. Overall, progression of disease was rapid during the first year, less rapid between 1 and 5 years of age, and slow between 5 and 10 years (Thorne and Newell, 2002).

Several studies from the developed world also show that while ART can substantially improve growth, growth remains a predictor of disease severity and survival even after the initiation of treatment (Carey et al., 1998). In addition to clinical symptoms, many children living with HIV may not attain normal developmental or growth milestones, including milestones for normal weight to height (NIAID, 2004). They may also be slow to reach milestones in motor skills, neurologic, and mental development, such as crawling, walking, and talking. Pediatric HIV disease is neurotrophic, involving the central nervous system, and as it progresses many children exhibit language compromise; cognitive defects, learning disorders, and resulting poor school performance; seizures; and other symptoms of HIV encephalopathy (a brain disorder)(Bruck et al., 2001). Psychological issues are compounded by ensuing family disruption, the burden of secrecy surrounding HIV status, and the discrimination directed at adults and children living with HIV. Pediatric HIV is a syndrome, presenting as a combination of medical, psychosocial, clinical, and other issues. Interventions are based on type of severity of the disorder(s), the amount of time available, the parent’s desires for the child, and the child’s health status (David-McFarland, 2004).

HIV infection may disrupt many of the social support systems that a child depends on for optimal development. Unlike many other illnesses, children with HIV are also more likely to experience parental illness and possible death, social stigmatization, and the prospect of lifelong adherence to complicated medical regimens (Steele et al., 2007). Postpartum stresses and emotional changes can also make it difficult for mothers to adhere to their HIV treatment regimens. The multigenerational nature of HIV infection highlights the importance of recognizing that a parent’s disease progression may affect his/her ability to characterize and respond to his or her child’s behavior. With more children living with HIV growing older, issues of treatment adherence, disclosure, and changing development needs present the need for continuing parental and family support at every stage of illness and child development stage.

**Annex C: UNAIDS Core Indicators for Monitoring the Declaration of Commitment on HIV/AIDS – 2008 Reporting**
10. Support for Children Affected by HIV and AIDS

As the number of orphaned and vulnerable children continues to grow, adequate support to families and communities needs to be assured. In practice, care and support for orphaned children comes from families and communities. As a foundation for this support, it is important that households are connected to additional support from external sources.

<table>
<thead>
<tr>
<th>Percentage of orphaned and vulnerable children aged 0–17 whose households received free basic external support in caring for the child</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PURPOSE</strong></td>
</tr>
<tr>
<td><strong>APPLICABILITY</strong></td>
</tr>
<tr>
<td><strong>DATA COLLECTION FREQUENCY</strong></td>
</tr>
<tr>
<td><strong>MEASUREMENT TOOL</strong></td>
</tr>
</tbody>
</table>
| **METHOD OF MEASUREMENT** | After all orphaned and vulnerable children aged 0–17 in the household have been identified, the household heads are asked the following four questions about the types and frequency of support received, and the primary source of the help for each orphan and vulnerable child. Each question is to be asked for each child.  
1. Has this household received medical support, including medical care and/or medical care supplies, within the last 12 months?  
2. Has this household received school-related assistance, including school fees, within the last 12 months? (This question is to be asked only of children aged 5–17.)  
3. Has this household received emotional/psychological support, including counselling from a trained counsellor and/or emotional/spiritual support or companionship within the last three months?  
4. Has this household received other social support, including socioeconomic support (e.g. clothing, extra food, financial support, shelter) and/or instrumental support (e.g. help with household work, training for caregivers, childcare, legal services) within the last three months?  

External support is defined as free help coming from a source other than friends, family or neighbours unless they are working for a community-based group or organization. |
| **Numerator:** | Number of orphaned and vulnerable children aged 0–17 who live in households that received at least one of the four types of support for each child (answered “yes” to at least one of questions 1, 2, 3 and 4) |
| **Denominator:** | Total number of orphaned and vulnerable children aged 0–17 |

For the purposes of this indicator, an orphan is defined as a child below the age of 18 that has lost both parents.
A child made vulnerable by HIV is below the age of 18 and:

i.) has lost one or both parents; or

ii.) has a chronically ill parent (regardless of whether the parent lives in the same household as the child); or

iii.) lives in a household where, in the last 12 months, at least one adult died and was sick for three of the four months before he or she died; or

iv.) lives in a household where at least one adult was seriously ill for at least three of the past 12 months.

INTERPRETATION

This indicator should only be monitored in settings with high HIV prevalence (5% or greater). The indicator does not measure the needs of the household or the orphan and vulnerable children. Additional questions could be added to measure expressed needs of families caring for orphans. The indicator implicitly suggests that all households with orphans and vulnerable children need external support; some orphans and vulnerable children are more in need of external support than others. Therefore, it is important to disaggregate the information by other markers of vulnerability such as socioeconomic status of the household, dependency ratio, head of the household, etc.

If sample sizes permit, it may be useful for programmatic purposes to investigate differences between values for this indicator for orphans versus other vulnerable children. It may also be useful to look at data disaggregated by age and duration of orphanhood, as both play a key role in determining the type of support needed. For example, an orphan whose parent(s) died 10 years ago will need support of a different kind from one whose parent(s) died within the past year.

When considering the four types of support separately, data for school-related assistance should be limited to children aged 5-17.

FURTHER INFORMATION

For further information, please consult the following website:

Annex D: Authorization to Release HIV-Related Information

HIPAA Compliant Authorization for Release of Medical Information and Confidential HIV* Related Information

This form authorizes release of medical information including HIV-related information. You may choose to release just your non-HIV medical information, just your HIV-related information, or both. Your information may be protected from disclosure by federal privacy law and state law. Confidential HIV-related information is any information indicating that a person has had an HIV-related test, or has HIV infection, HIV-related illness or AIDS, or any information that could indicate a person has been potentially exposed to HIV.

Under New York State Law, HIV-related information can only be given to people you allow to have it by signing a written release. This information may also be released to the following: health providers caring for you or your exposed child; health officials when required by law; insurers to permit payment; persons involved in foster care or adoption; official correctional, probation and parole staff; emergency or health care staff who are accidentally exposed to your blood, or by special court order. Under State law, anyone who illegally discloses HIV-related information may be punished by a fine of up to $5,000 and a jail term of up to one year. However, some re-disclosures of medical and/or HIV-related information are not protected under federal law. For more information about HIV confidentiality, call the New York State Department of Health HIV Confidentiality Hotline at 1-800-962-5065; for information regarding federal privacy protection, call the Office for Civil Rights at 1-800-368-1019.

By checking the boxes below and signing this form, medical information and/or HIV-related information can be given to the people listed on page two (or additional sheets if necessary) of the form, for the reason(s) listed. Upon your request, the facility or person disclosing your medical information must provide you with a copy of this form.

I consent to disclosure of (please check all that apply):

- [ ] My HIV-related information
- [ ] Both (non-HIV medical and HIV-related information)
- [ ] My non-HIV medical information

Information in the box below must be completed.

Name and address of facility/person disclosing HIV-related and/or medical information:
________________________________________________________
________________________________________________________

Name of person whose information will be released:

Name and address of person signing this form (if other than above):

Relationship to person whose information will be released:

Describe information to be released:

Reason for release of information:

Time Period During Which Release of Information is Authorized
From: ____________________________ To: ____________________________

Disclosures cannot be revoked, once made. Additional exceptions to the right to revoke consent, if any:

Description of the consequences, if any, of failing to consent to disclosure upon treatment, payment, enrollment or eligibility for benefits (Note: Federal privacy regulations may restrict some consequences):

All facilities/persons listed on pages 1, 2 (and 3 if used) of this form may share information among and between themselves for the purpose of providing medical care and services. Please sign below to authorize.

Signature ____________________________ Date ____________________________

*Human Immunodeficiency Virus that causes AIDS
** If releasing only non-HIV medical information, you may use this form or another HIPAA-compliant general medical release form.
HIPAA Compliant Authorization for Release of Medical Information and Confidential HIV* Related Information

Complete information for each facility/person to be given general medical information and/or HIV-related information. Attach additional sheets as necessary. It is recommended that blank lines be crossed out prior to signing.

Name and address of facility/person to be given general medical and/or HIV-related information:

Reason for release, if other than stated on page 1:

If information to be disclosed to this facility/person is limited, please specify:

Name and address of facility/person to be given general medical and/or HIV-related information:

Reason for release, if other than stated on page 1:

If information to be disclosed to this facility/person is limited, please specify:

The law protects you from HIV-related discrimination in housing, employment, health care and other services. For more information call the New York State Division of Human Rights Office of AIDS Discrimination Issues at 1-800-523-2437 or (212) 480-2522 or the New York City Commission on Human Rights at (212) 306-7500. These agencies are responsible for protecting your rights.

My questions about this form have been answered. I know that I do not have to allow release of my medical and/or HIV-related information, and that I can change my mind at any time and revoke my authorization by writing the facility/person obtaining this release. I authorize the facility/person noted on page one to release medical and/or HIV-related information of the person named on page one to the organizations/persons listed.

Signature __________________________   Date __________________________

(Signature of information or legally authorized representative)

If legal representative, indicate relationship to subject: __________________________

Print Name __________________________

Client/Patient Number: __________________________

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HIPAA Compliant Authorization for Release of Medical Information and Confidential HIV* Related Information

Complete information for each facility/person to be given general medical information and/or HIV-related information. Attach additional sheets as necessary. Blank lines may be crossed out prior to signing.

Name and address of facility/person to be given general medical and/or HIV-related information:

________________________________________________________________________

________________________________________________________________________

Reason for release, if other than stated on page 1:

________________________________________________________________________

If information to be disclosed to this facility/person is limited, please specify:

________________________________________________________________________

Name and address of facility/person to be given general medical and/or HIV-related information:

________________________________________________________________________

________________________________________________________________________

Reason for release, if other than stated on page 1:

________________________________________________________________________

If information to be disclosed to this facility/person is limited, please specify:

________________________________________________________________________

Name and address of facility/person to be given general medical and/or HIV-related information:

________________________________________________________________________

________________________________________________________________________

Reason for release, if other than stated on page 1:

________________________________________________________________________

If information to be disclosed to this facility/person is limited, please specify:

________________________________________________________________________

If any/all of this page is completed, please sign below:

Signature __________________________________________ Date ____________

Client/Patient Number: ________________________________
Annex E: Child Bereavement Network Guidelines for Health and Social Workers

GUIDELINES FOR BEST PRACTICE

Safety
- Is there a documented policy to ensure the overall safety of children using your service/s? Does this policy encompass the whole range of work undertaken by paid/voluntary staff e.g. individual/group work, transport by volunteers, home visits?
- Does the policy incorporate a set procedure for the recruitment of paid staff and volunteers?
- Do paid and voluntary staff receive training and supervision to ensure the overall safety of children using your service?
- Do you work within the legislative framework and guidance, specifically the Children Act 1989, Working Together to Safeguard Children documents: Safe from Harm (Home Office), Duty to Care (DHSS Northern Ireland) and the Children (Scotland) Act 1995?
- Is there a documented policy on confidentiality? Is this reviewed on a regular basis and agreed with paid/voluntary staff?
- Is there a documented policy to ensure the personal safety of paid/voluntary staff? Is this policy reviewed and evaluated regularly in consultation with all staff?

Practice Context
- Are the principles embodied in the GBN Belief Statement incorporated into your practice and the service/s you provide? Do you regularly review your approach to your work? As an organisation, do you consult with paid/voluntary staff during this process?
- Is your documented policy on confidentiality fully discussed and agreed with the individual child, the parent/s, other family members and caregivers?
- Is there a documented health and safety policy?
- Are there procedures in place to ensure data protection?
- Are documented policies and procedures reviewed regularly to comply with legal requirements?
- Is your service appropriately resourced? Do you have reliable access to a safe space, room or premises? Do you have a budget to buy equipment?

Quality and Accountability
- Do you have procedures to enable you to monitor, evaluate and review the service/s you provide on a regular basis?
- Do you regularly undertake a needs assessment to review the appropriateness of your work or service/s? Do you liaise with users, key referral agencies, staff and other professionals working in your catchment area regarding any proposed service development? Do you have a procedure to ensure effective liaison with other local, regional or national organisations offering similar services?
- Is there a documented policy to ensure that all paid/voluntary staff are appropriately trained to work with bereaved children, their families and other caregivers? Are training needs regularly reviewed? Are all paid/voluntary staff offered regular opportunities to update their skills? Do you have a training budget?
- Is there a documented policy on supervision? Are all paid/voluntary staff appropriately supervised? Are paid/voluntary staff consulted on a regular basis to agree their supervision needs?
- Do you encourage feedback on your service from users, key referral agencies and professionals? Is there a documented and accessible complaints procedure for users, key referral agencies, paid/voluntary staff and the public?
- Do you have a statement of purpose or mission statement plus clear aims to define the remit of your service? Is there a business plan, including a funding strategy to ensure the sustainability of your service? Do you publish and circulate an annual report to key referral agencies and users?
- Is there a written definition of your service/s, which clearly sets out details of the information, guidance and support you offer? Is this regularly reviewed and updated? Within the remit of your service, is this information circulated to key referral agencies and potential users in the form of a publicity leaflet?

Equality
- Is there a documented and proactive equal opportunities policy?
- Do you regularly undertake a needs assessment to review the accessibility and appropriateness of your service/s in terms of equality of opportunity?
- Do you regularly review your service/s to identify and amend any anti-discriminatory practice?
- Are you able to respond to the needs of bereaved minority ethnic children, especially in terms of language?
- Are you able to respond to the needs of bereaved disabled children or those with learning disabilities?
- Do you liaise with other organisations to raise awareness of the needs of bereaved children, their families and other caregivers?

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