# Resource Mapping and Needs Assessment for Community Child and Adolescent Mental Health Services

A Report on Findings, Analysis and Recommendations

Preliminary Work undertaken for DWCD Community Child & Adolescent Mental Health Service Project

Supported by Dr. R.N. Moorthy Foundation for Mental Health & Neurological Sciences

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**Dept. of Child & Adolescent Psychiatry** 

National Institute of Mental Health & Neuro Sciences (NIMHANS), Bangalore

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# **Executive Summary**

This preliminary component of the DWCD Community Child & Adolescent Mental Health Service project sought to conduct an in-depth assessment of community child and adolescent mental health needs and resources, with the following objectives:

- i) To map the types of child and adolescent mental health resources and services that communities can access.
- ii) To identify the various types and cadres of service providers and assess their knowledge, skills and capacities with regard to provision of services to children and adolescents.
- iii) To identify vulnerable populations and understand community and caregiver priorities and concerns about child and adolescent mental health.
- iv) To develop a comprehensive database of service providers and services and list gaps therein in order to enable the establishment of the comprehensive community-based service model.

Over the 4-month period of this preliminary work, needs assessments and preliminary orientation and sensitization programs were conducted for stakeholders in three key sectors that work with children, namely health, education and welfare. Interviews, focus group discussions and workshops were conducted to understand the types of mental health problems common in urban slum communities, the mental health services available to children and adolescents, as well as the knowledge and skill needs and gaps of the service providers. The needs assessment was located in Bangalore South Zone targeting 13 primary healthcare centres serving vulnerable urban populations (slum communities), and 46 anganwadis, 21 government schools and RBSK functionaries located within/ serving these communities. Additionally, 32 child care institutions (CCIs), governmental and nongovernmental, working with children in difficult circumstances i.e. with street and working children, orphan and abandoned children, HIV infected/ affected children, children with disability and children affected by gender and sexuality vulnerabilities, participated in the needs assessment workshops.

# **Summary of Needs Assessment and Resource Mapping Activities**

Sector	Type of Staff Targeted	No. of Staff	No. of Workshops
Health	Medical Officers	10	1
	ANM/Link Workers	40	2
	RBSK School Health Team Doctors	21	1
Education	Teachers/ Principals from 21 Government/ Aided Schools	32	2
Welfare	Anganwadi Teachers	46	2
	Anganwadi Supervisors/ DWCD Staff	23	1
	Staff from 32 CCIs	60	7
Total		232	16

Key findings of the resource mapping and needs assessment exercise:

#### Health Sector:

There is some basic knowledge on disability but the sector lacks knowledge and skills on systematic screening and intervention response. Emotional and behaviour problems go largely unrecognized. Communities also do not seek child mental health services at PHC level as they are aware that this is a gap in basic health services. Existing structures such as

the mental health and Sneha clinic are under-utilized and are potential spaces in which child and adolescent mental health services can be introduced at PHC level, along with community awareness creation by link workers.

Within the sector, the RBSK school health team has the strongest potential, to deliver child and adolescent mental health services as they cover government schools and anganwadis. Currently, their function is restricted to (disability) screening and referral. However, there are plans to extend the scope of their work to include systematic screening, referral and first-level responses to disability as well as emotional and behavioural issues in children.

# **Education Sector**

Both school teachers and principals recognize the role of the school in child development and managing children's emotions and behaviour. However, this recognition has not translated into any kind of systematic or sensitive practice. Preventive and promotive mental health activities are hardly carried out. There is a reliance on external resources for this. While they acknowledge the need for responding to children with acute issues, academic/emotional/behavioural, they are reluctant to play an active part in this; stating that they are already over-burdened with administrative duties, they are unwilling to take on even basic first-level response to provide mental health support to identified children. They are, however, willing for external professional resources to assist them in this task. One possible strategy is to identify two to three 'motivated' teachers in each school and train them in basic/ first level response to support child mental health needs in schools.

#### Welfare Sector

### Anganwadis

Anganwadi workers are motivated and enthusiastic to engage in depth child mental health work. While their training has some components of child development and mental health, these appear inadequate both conceptually and in terms of a skill base. It would be strategic to strengthen mental health and child development components in job training centres (JTC) so that newly recruited workers have a clear child mental health orientation. Further, for existing workers, on-job training in the use of simple screening tools for early identification of developmental delays and disabilities, more focussed child development and stimulation activities, using low-cost aids, would give pre-school children a better start.

#### Child Care Institutions

Most CCIs run institutions that provide children with basic needs. However, despite children's coming to them from difficult circumstances, often with experiences of loss, grief and trauma, mental health needs are not an active part of the institutional care provision. This seems to be mainly because CCI staff have not the knowledge and skills to address children's emotional and behaviour problems; they are not equipped with the methods and techniques to respond to children with special needs, and even less so when dealing with loss, grief, trauma and abuse issues. Thus, there is a need to assist CCIs with training and capacity building in these areas, so they may better meet children's mental health needs.

\*

In summary, child and adolescent mental health services are practically absent in various child care systems. There is little knowledge about identification about identification and first-level response, very little skill even where problems are recognized. Thus, most children's

mental health needs go unattended. Given competing priorities within these sectors/ services, that mainly pertain to basic survival needs, child mental health does not feature among these services. The systems that govern these service providers also contribute to this state by lack of mental health orientation, on the one hand, and lengthy and cumbersome bureaucratic processes, on the other. In all this, the child falls through the cracks.

That said, all the sectors and service providers that work with children, upon reflection, opined that child mental health is a critical area to work on. This opinion came in the context of recent concerns around child abuse and child protection, and the debates around parenting, discipline, the role of educational institutions, in wholesome growth of children, towards a sensitive, responsible and competent citizenry. Thus, the future potential of this project was considered to be immense, that is, to work with service providers to incorporate child and adolescent development and mental health principles and services into their work.

# I. Project Rationale and Objectives

#### 1. Need for Child and Adolescent Mental Health Service Assessment

There is a gap in child and adolescent mental health services in the Indian context, wherein screening and early intervention and/or psychosocial care provision by non-specialists, exists to an extremely limited extent; and where provision of mental health services are largely restricted to curative services in tertiary care facilities, thereby limiting access to most children in need. The scope of such services and the issue of who will deliver them need further elucidation. The proposed activity seeks to undertake a needs assessment that maps out available child mental health resources and services, identify gaps and learning needs in the skills and capacities of the service providers and to understand what some of the most common child and adolescent mental health concerns are within an urban community i.e. what issues parents and caregivers have to frequently contend with.

India is becoming more urban. As of 2011, over one-third of the population resides in urban areas and over the coming decades, this is expected to increase to over 50% of the population<sup>1</sup>. Rapid urbanization creates communities through a chaotic process that mixes economic migrants and other vulnerable socio-economic groups, concentrating them in urban slums. Urban slums gather the urban poor into unplanned, informal settlements lacking water, sanitation, basic housing, health and other essential infrastructural facilities, as well as adequate means of livelihood. The process of rapid urbanization also takes away people's psychosocial support. Identity, recognition and participation are embedded in a shared community and location. Urbanization dislocates individuals and households from long-standing kinship based communities, forcing them into informal settlements, to form communities of strangers<sup>2</sup>. According to the UN Habitat, in addition to deteriorated living conditions and economic problems, these informal settlements/ slums are also characterized by high rates of gender disparities, social exclusion and marginalization, lack of social interaction and high incidence of crime<sup>3</sup>.

The National Urban Health Mission (NUHM), India, which also echoes the UN Habitat report, discusses the need to view vulnerability of these urban populations not just in relation to poor economic status but also in terms of social factors such as gender, disability, singleness, age, stigmatic and debilitating illness and others. The NUHM therefore also states the need to develop services for vulnerable groups in keeping with principles of seamless continuum of care and multi-disciplinarity of services. Towards this end, the NUHM recommends the process of mapping to capture the problems and healthcare needs of vulnerable groups. 5 out of 14 recommendations in the NUHM's section on vulnerable populations refer to the significance of mapping including: identification of vulnerable groups across residential, habitation and social axes; social relations and issues of access to healthcare; and service provision. The NUHM also makes special mention of vulnerable children's groups such as street children, and how custodial populations such as

<sup>1</sup> Report and Recommendations of the Technical Resource Group for the National Urban Health Mission, 6th February 2014

<sup>&</sup>lt;sup>2</sup> Schoeller-Diaz,D.A, Lopez, V.A, Kelly, J.J.I, Patel, R.B.P (2012). Hope in the Face of Displacement and Rapid Urbanization: A Study of the Factors that Contribute to Human Security and Resilience in Districto de Aguablanca, Cali, Columbia. Harvard Humanitarian Initiative. Working Paper Series, September 2012

<sup>&</sup>lt;sup>3</sup> State of World's Cities 2010/2011: Bridging the Urban Divide. UN Habitat, Nairobi

orphanages and child care institutions are often excluded from surveys and mapping/assessment exercises<sup>4</sup>.

Further, the Rashtriya Bal Swasthya Karyakram (RBSK) and the Rashtriya Kishor Swasthya Karyakram (RKSK) services launched under the NRHM has now been extended to the NUHM. RBSK focuses on early intervention services that target children between ages 0 to 6 years as well as older children, particularly in urban slums, with developmental delays and disabilities<sup>5</sup>; RKSK focuses on adolescent health with a view to improving nutrition, sexual and reproductive health, mental health and preventing substance abuse, and preventing injuries and violence including addressing gender-based violence issues<sup>6</sup>.

Part of the roll-out of the RBSK services entail identification of nodal persons for screening/ early intervention services and mapping of private and public facilities/ institutions for treatment of specific conditions<sup>7</sup>. Similarly, part of the implementation of RKSK services suggests a situational analysis of adolescent health issues and service availability<sup>8</sup>.

To the best of our knowledge, thus far, no such comprehensive assessments or mapping of child and adolescent mental health vulnerabilities, needs and services had been undertaken. Thus, a comprehensive mapping-assessment, in accordance with the NUHM recommendations, will enable the Dept. of Child and Adolescent Psychiatry to then respond to the population needs of one of the most vulnerable groups i.e. children and adolescents, by establishing a community-based child and adolescent mental health service model. Initial discussions with the NIMHANS Well-being Centre indicated both the intense need and the challenges encountered in undertaking community-based child and adolescent mental health work; amongst these was the need to implement a mapping-needs assessment in order to be able to design an appropriate service delivery model. Support is available to establish such a broad-based service model that will entail service delivery at primary, secondary and tertiary levels with a view to providing preventive, promotive and curative child and adolescent mental health care.

# 2. Objectives

The proposed activity therefore seeks to conduct an in-depth assessment in a defined geographic community, with the following objectives:

- i) To map the types of child and adolescent mental health resources and services that communities can access.
- ii) To identify the various types and cadres of service providers and assess their knowledge, skills and capacities with regard to provision of services to children and adolescents.
- iii) To identify vulnerable populations and understand community and caregiver priorities and concerns about child and adolescent mental health.

<sup>4</sup> Report and Recommendations of the Technical Resource Group for the National Urban Health Mission, 6<sup>th</sup> February 2014

<sup>&</sup>lt;sup>5</sup> Ministry of Health & Family Welfare (2013). Rashtriya Bal Swasthya Karyakram (RBSK). Child Health Screening and Early Intervention Services under NRHM. Government of India.

<sup>&</sup>lt;sup>6</sup> Adolescent Health Division, Ministry of Health & Family Welfare (2014). Rashtyira Kishor Swasthya Karyakram: Operational Framework, Translating Strategy into Programmes. Government of India.

<sup>&</sup>lt;sup>7</sup> Ministry of Health & Family Welfare (2013). Rashtriya Bal Swasthya Karyakram (RBSK). Child Health Screening and Early Intervention Services under NRHM. Government of India.

<sup>&</sup>lt;sup>8</sup> Adolescent Health Division, Ministry of Health & Family Welfare (2014). Rashtyira Kishor Swasthya Karyakram: Operational Framework, Translating Strategy into Programmes. Government of India.

iv) To develop a comprehensive database of service providers and services and list gaps therein in order to enable the establishment of the comprehensive community-based service model (refer above).

# 3. Proposed Activities

# **Activity 1: Mapping of Existing Community Services**

Identification and mapping of existing community child and adolescent mental health resources will be undertaken as a first step. The mapping exercise will include a needs assessment to identify the types of services provided by the agency/service; special emphasis will be laid on mapping of school counselling services in terms of their availability, qualifications and activities. All types of agencies involved in child and adolescent mental health, both public and private, working in the areas of health education and welfare, including agencies responding to vulnerable child populations (such as street children etc) will be mapped. In-depth interviews with be conducted with key informants (including administrators and policy makers) from the above-mentioned public and private institutions/ agencies, as well the RBSK and RKSK services.

## Activity 2: Assessment of Skills, Capacities and Learning Needs of service providers

Based on initial discussions with the NIMHANS Well-being Centre, it is deemed best that both mapping and skills and capacities assessment activities be started with ANMs and Aanganwadi workers, who will serve as an entry point into the communities. Initial key informant interviews and focus group discussions with them could then lead to identification of other stakeholders within the community, including parents and caregivers.

Following the initial mapping and identification exercise, orientation and sensitization workshops will be held for non-governmental organizations, public health professionals, private health professionals, schools/teachers and government departments (Education, Health, Labour, Women & Child Development, Disability, Social Justice, NRHM, JJ Act functionaries, and Panchayat System); teachers, doctors, Anganawadi Workers, ANM's and ASHA Workers. These workshops (see below for details), for staff of various types, identified through the service mapping, will focus on i) sensitizing staff to child and adolescent mental health needs; ii) identifying the knowledge and skill gaps of the staff, to better understand their learning needs for service delivery.

# **Activity 3: Assessment of Child Mental Health Issues in the Community**

An understanding of common child and adolescent mental health issues will be obtained through key informant interviews and focus group discussions in the community, with parents and caregivers, including teachers and NGO workers. The discussions will centre on child-rearing practices, disciplining, parent-child communication patterns, parent/ caregiver concerns about children's well-being and behaviour. It will also include identification and understanding of vulnerabilities of children and adolescents in difficult circumstances, such as street children, institutionalized children and others.

## 4. Learning Outcomes

• To understand child and adolescent mental health vulnerabilities, needs and services in the context of rapid urbanization.

- To learn about and disseminate information on the types of child and adolescent mental health services and service providers, including their needs and capacities to serve their target populations.
- To sensitize and orient various cadres of staff from public and private agencies (health/ education/women and child) on the mental health needs of children and adolescents as well as potential models of interventions.

# **5. Future Plans: Use of the Resource Mapping and Needs Assessment Findings**

The resource mapping and needs assessment work done in this project has created the platform to launch a long-term community child and adolescent mental health service delivery program. Such a program has been planned and support from the Dept. of Women and Child Welfare (DWCD) is forthcoming. Based on the R.N. Moorthy project assessment findings, the DWCD-supported program comprises a comprehensive plan to provide community-based Child and Adolescent mental health promotive, preventive, and curative care in urban and later in rural sites through direct service delivery and training and capacity building of child care workers from community-based governmental and non-governmental agencies/institutions and professionals, including schools, NGOs, anganwadi workers and PHC health workers.

# II. Mapping of Community Child Care and Mental Health Services

# 1. Expansion of Proposed Geographic Locations

As per the original proposal, the sectors for engagement in the needs assessment were to drawn from some of the localities of the urban ward of BTM Layout (ward nos. 172 and 176) in anticipation that this would further strengthen the activities of the NIMHANS well-being center also located in this area. However, it was found that only 2 PHCs i.e. in Taverkere and Madiwala, lay in this geographic area. It was felt that the inclusion of only two PHCs in the assessment would not be representative of PHC/staff needs and capacities i.e. that our understanding of child and adolescent mental health needs and issues would be extremely limited. Further, since future plans include provision of community-based child and adolescent mental health services through PHCs, a greater number of PHCs would be required to implement and evaluate interventions, and to be able to draw conclusions that are valid and generalizable.

Therefore, the geographic locations of the project were extended to include 13 PHCs and their respective catchment populations, namely the slum areas that they serve. For purposes of convenience, it was decided that these PHCs would be selected from Bangalore South Zone, a large enough urban area (comprising of a total of 23 PHCs/ catchment areas), offering the vulnerable slum populations whom the project particularly desired to target for assessment and future intervention.

# Postponement of Activity 3: Assessment of Child Mental Health Issues in the Community

As a result of the extension of geographic locations of the project and a consequent increase in service providers, the project was unable to deliver proposed activity on assessment of child mental health issues in the community, within the 4-month project time frame. Further, the mapping and orientation of service providers proved to be longer and more time-consuming than originally anticipated for two reasons: i) difficulty in obtaining permissions from government departments (further discussed under 'Operational Challenges' section of this report); ii) there were several groups of service providers, including some new ones under the NUHM, which the project had not factored under the original plan. Thus, instead of 6 workshops for 117 participants, as per original plan, the project conducted a total of 16 workshops for 232 staff from health, education and welfare sectors. (See table 2 below).

However, given the importance of the completing community assessment, and understanding child mental health issues from the community perspective, in order to develop and implement interventions (as planned for the continuation of this project) this activity is being implemented with support from the Dept. of Women and Child Development (DWCD). The community assessment findings will be made available by January 2014—and will be used along with the R.N. Moorthy project-supported service provider findings, to develop community-based child and adolescent services and interventions.

# 2. Selection of Community Services and Infrastructure

## **Primary Healthcare Centres**

Following the decision to implement assessment activities in 13 PHCs, the team obtained a list of the 23 PHCs in Bangalore South Zone. 13 PHCs and their catchment areas were selected using the following criteria: i) PHC catchment area being inclusive of at least one

slum population (preferably a larger slum area); ii) PHC catchment area having within or near it, at least one government school that is attended by children from the slum.

Thus, the first round of mapping entailed visits to each of the 13 PHCs selected to ensure that the inclusion criteria were met and to obtain basic information on the their staffing, the number of government schools and anganwadis serving the slum areas of the selected PHC catchment populations. (Refer to annex 1 for details).

#### **Communities**

While each of the selected PHCs serves a large catchment area, the project chose to focus on the slums within the larger PHC catchment area. This is because slums represent the vulnerable communities created by rapid urbanization processes; comprised of the urban poor, these communities usually lack water, sanitation, basic housing, health and other essential infrastructural facilities, as well as adequate means of livelihood. As a result of such deprivations, slums are also characterized by high rates of gender disparities, social exclusion and marginalization. Children and adolescents living in such situations are therefore most likely to be deprived of developmental needs and opportunities as well as to be exposed to many psychosocial risks. Thus, since some of the most vulnerable children live in these parts of the catchment areas, and the objective of the project is to understand (with a view to later serving) the needs and problems of the most vulnerable, slums formed the target communities for assessment.

# **Anganwadis and Schools**

Likewise, each PHC catchment population is served by an average of 15 to 20 government and aided schools and about 15 anganwadis. Given that slum communities were selected as the unit of analysis to represent community perspectives on child mental health issues, schools selected using the following criteria: i) government (and aided) schools; ii) government schools serving the children of the slum community selected. The assumption is that children attending government schools are more likely to be from lower socio-economic groups and therefore more vulnerable to child mental health issues; based on this assumption, children from slums are most likely to attend the government schools that are can access/ are in proximity to their communities.

Similarly, anganwadis located within the selected slum communities were selected for assessment. The assumption here is that most young children within the slum would avail of early childcare services at anganwadis that are nearest to them i.e. access the anganwadis located within the slum. Also, due to socio-economic deprivations, resulting in nutritional deficiencies and lack of adequate and appropriate care, young children residing in slum communities are more likely to be at risk of developmental delays and disorders than in better-off households outside the slum.

In all, 21 government (and/or aided) schools and 46 anganwadis were selected, from across the 13 PHC catchment areas, for the initial assessment.

#### **Child Care Institutions (CCIs)**

Although the intention of this project was to map services within a certain geographic area, it was difficult to map CCI services in accordance with this because i) CCIs may be located in one place but reach several geographic areas, as per their objectives and services; ii) some CCIs serve mobile/ floating populations such as street children, so as such, they cannot limit

their services to any particular area within Bangalore city; iii) there are many CCIs of varying types, offering different services but no clear record/ listing of all of them.

Therefore, a list of CCIs working with children was obtained from the Department of Women and Child Development. CCIs (including government and non-governmental agencies) were listed for Bangalore district. To this were added 24 NGOs registered under the J.J. Act (and not included in the DWCD list). Thus, a first level of mapping was done using the internet to obtain the names/ basic details of 93 CCIs. Of these, 90 were selected for the next level of mapping and 3 were excluded.

The inclusion criteria for CCIs were therefore the following: i) child care institutions registered by DWCD and/or the Juvenile Justice (J.J.) Act; ii) organizations serving urban children i.e. by way of location<sup>9</sup>; iii) organizations whose activities focus on child development, psychosocial care (including care, protection and rehabilitation), early childhood care and education and adoption; iv) organizations serving the needs of vulnerable children, namely children in difficult circumstances and/or from lower socioeconomic groups.

The exclusion criteria for the CCIs were: i) child care institutions not registered under DWCD or J.J. Act; ii) organizations that located and focussed their activities in rural areas for rural children (because the needs and contexts of children residing in rural areas are different from those living in urban areas); ii) organizations that cater to children from higher socioeconomic groups (and that therefore often demand a fee/ charge for service).

The 90 CCIs were placed in 5 broad categories based on typology of children served and /or common service needs/ capacities necessary in a service as follows:

Category 1: Street & Working children

Category 2: Orphan and Abandoned Children (including infants and pre-school age children)

Category 3: Children with Disability

Category 4: Children infected and/or affected by HIV

Category 5: Children Affected by Gender and Sexuality Vulnerabilities

(Refer Annex 6 (a) for list of CCIs contacted and 6 (b) for categorization of CCIs)

Table 1: Summary of Needs Assessment and Resource Mapping Activities

Sector	Type of Staff Targeted	No. of Staff	No. of Workshops
Health	Medical Officers	10	1
	ANM/Link Workers	40	2
	RBSK School Health Team Doctors	21	1
Education	Teachers/ Principals from 21 Government/ Aided	32	2
	Schools		
Welfare	Anganwadi Teachers	46	2
	Anganwadi Supervisors/ DWCD Staff	23	1
	Staff from 32 CCIs	60	7
Total		232	16

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<sup>&</sup>lt;sup>9</sup> While many of the children served by urban child care institutions may be drawn from rural areas (such as street children, runaways and railway children), at the time of identification they were living in urban areas, enduring risk factors posed by urban living conditions and challenges.

# 3. Obtaining Permissions

Permissions from the relevant government departments were obtained through several meetings with the concerned officers-in-charge (See table 2 below). Given that the project targeted persons working directly to provide services for children and communities, permissions were first sought from those directly supervising them. However, their direct supervisors required permissions from higher authorities and so successive rounds of permissions were sought from officers holding higher positions within the concerned departments. Each visit/ meeting consisted of introducing the concerned party to the projective objectives and purpose, along with submission of letters. Time for obtaining permissions varied from 2 to 3 months as due internal communications and official processes took considerable time for completion within the departments.

**Table 2: Permissions Obtained** 

Target Group	1st Level	2nd Level	3rd Level
	Permissions	Permissions	Permissions
PHC staff (Medical	Medical Officer	Health Officer,	Joint Commissioner,
Officers/ Health		Bangalore South Zone	Health
Assistants/ Link		(BBMP Health)	Chief Health Officer
Workers)		Medical Health Officers	(BBMP Health)
Rashtriya Bal		District Program	Deputy Director,
Swasthya Karyakram		Medical Officer	RBSK
(RBSK) School Health		District Health Officer	National Rural/
Team		(Dept. of Health)	Urban Health
			Mission Director
Government School	School Principal	Block Education	Deputy Director for
Principals and		Officers	Public Instruction
Teachers		(Dept. of Education)	(Dept. of Education)
Anganwadi Workers	-	Child Development	Deputy Director,
		Project Officer (CDPO)	Dept. of Women and
		(DWCD)	Child Development
			Director, DWCD
			(DWCD)

# III. Needs Assessment of Capacities and Services

This section presents the assessment findings obtained through interviews, focus group discussions and awareness/ sensitization workshops conducted for the three sectors working with children in various capacities, namely health, education and welfare. The health sector assessment focuses on the public health system only, namely the primary healthcare system, through assessment of knowledge and skills of medical officers, ANMs and link workers; the RBSK school health team also falls under the health sector and works in collaboration with the PHCs. The education sector assessment focuses on government and aided schools through assessment of knowledge and skills of principals and teachers. The welfare sector focuses on anganwadi (teachers) and staff of child care institutions. The findings from each sector, and its respective individual stakeholders, are analysed and recommendations made for the community child and adolescent mental health service project planned.

# 1. Health: Primary Health Care System

The PHC system caters immunization, nutrition and health needs of a number of children. This is an important contact point to look at developmental and child mental health issues, especially screening, early identification and referral issues. Further, the National and District Mental Health Programs strongly envisage provision of basic child mental health services in the PHC. Towards this, many initiatives have been recommended. These include weekly mental health clinics and adolescent health clinics (Sneha Clinics) and child development initiatives through the RBSK school health teams (which run under the Dept. of Health). The PHC link workers, through their community outreach work also provide opportunities for identifying and providing care to children and adolescents with mental health issues. There are also likely to be additional possibilities of providing child mental health care at PHC level when the NUHM becomes operational.

Therefore, the needs assessment included:

- Interviews and workshops with medical officers from selected (13) PHCs
- Assessment and sensitization Workshops with ANMs and link workers from selected (13) PHCs
- Focus group discussions and awareness workshops for 20 RBSK doctors

Section 1 on the PHC system presents the findings and discussions from these interviews and workshops, and makes recommendations accordingly.

#### 1.1. Health Assistants/ ANMs and Link Workers

40 primary health care (PHC) staff, including auxiliary nurse midwives (ANMs)/ health assistants and link workers were provided with a one-day orientation session on psychosocial and mental health issues in children residing in vulnerable urban communities. The workers were drawn from the selected 13 PHCs. (See annexe 2 for list of slums/ areas covered).

# **Objectives and Content of Orientation Workshop**

The objectives of the orientation workshop were:

- To introduce our community project and how we will support your work in the next few years.
- To provide an orientation on some key areas of working with children in the community:
  - Child development

- Identification of disability
- Common emotional and behaviour problems
- Understanding your perception on your role in community child mental health
- Identifying needs/ areas for training & capacity building.

# The orientation workshop included the following content:

- Key areas of child development: children's developmental needs and the types of support and interventions they require to promote age-appropriate growth/ development.
- Disability basics: Identification of disabilities, including the 10 question screening tool;
   basic responses to disability
- Emotional and behaviour problems in children: signs and symptoms of emotional and behaviour problems/ indicators for identification
- Contexts of children's emotional and behaviour problems, including child abuse (neglect, physical abuse and sexual abuse)
- o The role of PHC staff in community child mental health

# PHC Staff Knowledge and Skills: Observations and Discussions from the Orientation Workshop and Implications for Future Training & Capacity Building

# a) Knowledge of Child Development

PHC staff's knowledge of key areas in child development largely pertain to physical growth and development, and that too, from a (mal)nutrition perspective. Within this, their perception of growth is more about height and weight gain rather than physical milestones—which is not surprising given that they come from a primary (child) health care perspective, where these are about the only indicators of physical development, and where mental health/child development/ disability frameworks are not used.

Health workers also have some knowledge of developmental milestones, but these are restricted to infants and very young children. They know little about developmental milestones for children above the age of two. Again, this is also possibly because they largely provide child health services to this group. Thus, they have almost no knowledge about middle childhood (ages 7 to 12 years) and about adolescents (ages 13 to 18), although there was some mention of physical developmental stages/ changes in adolescence and some adolescent needs and issues on sexuality and conduct were mentioned, albeit from a negative/ problem perspective (i.e. inappropriate/ harmful behaviours relating to sexuality, substance abuse and other anti-social behaviours). Further, while this knowledge pertains in part to physical and social development, they have no knowledge in other domains of child development, such as language, emotional and cognitive development, and they were unable to distinguish between the five domains of child development—this was so even later in the session, when information on the key domains had been discussed, they were unable to think within a child development framework, during their discussions on contexts of emotional and behaviour problems in children.

# b) Identification & Response to Developmental Disability

The PHC staff said that the severe acute malnutrition (SAM) camps where children with SAM are brought by caregivers, for treatment and education, serve as opportunities for

identification of disability. When asked about signs and symptoms they might look for to identify disability, they mentioned children who:

- have visual impairment/ hearing problems
- cannot walk or sit up
- have seizures
- have drooling issues
- show 'peculiar behaviours' such as being inattentive or having no eye contact
- have no self-help skills (older children)
- have speech delays/ problems

There are no protocols or systematic questioning processes by which they identify developmental disabilities in children. During nutrition screening camps, while they are conducting anthropometric surveys, they 'generally' observe the children and might find some signs of disability. Sometimes, parents report to health workers about their child having disability and request assistance/ ask where to go. No disability awareness programs are conducted by health workers; health workers also come to know about children with disability through their home visits (made for other health programs and interventions).

Health workers' response includes referring the child and the family to a child specialist or hospital such as Indira Gandhi Institute for Child Health. Sometimes they or the PHC medical officers may directly refer them to NIMHANS but they tend not to do this too often because of the stigma and fear attached to seeking care at a mental health institute; therefore, they refer them to child health facilities/ specialists first, who may in turn refer them to NIMHANS. Health workers were not always aware of the concept and/or location of special schools facilities.

When asked about typical family responses to children with disability, the health workers did not appear to be very clear on what these are. However, contrary to the information provided by the medical officers of PHCs, health workers claim that there is no gender discrimination amongst children with disability i.e. that female children with disability are not mistreated or neglected, nor, according to health workers, are children with disability discriminated against by the family, with regard to food and other basic care. Families, especially in urban areas, do not resort to traditional medicine as a means to 'curing' disability. However, health workers have observed that older children or adolescents, especially girls tend to be 'hidden' or parents do not report or talk about their having an older child with disability (they are more likely to report/ seek assistance when they have young children with disability). This indicates that there are age and gender issues that play out with regard to disability and how/ for whom assistance is sought.

# c) Indicators of Emotional and Behaviour Problems in Children

Health workers have no knowledge or orientation on emotional and behaviour problems in children. While they know about/ are able to describe the social/ familial contexts in which such problems may occur i.e. families in which children are neglected, where there are alcohol problems or marital conflict, they are unable to connect the context to emotional and behaviour problems. They are not able to see how a context might impact or give rise to emotional and behaviour problems in children. Their lack of observation and knowledge on children's emotions and behaviours was apparent in that they were unable to name common emotions and underlying or related behaviours that children experience in the face of

provocation or difficult situations. In sum, their perspective on emotional development/problem issues continued to be from a nutrition and physical development paradigm.

# d) Perception of Role in Community Child Mental Health and Recommendations for Integrating Child Mental Health Issues into the PHC System

PHC staff/ health workers felt that they could play a dual role in community child mental health:

- Creating awareness on child mental health and disability through their health education sessions and periodic community meetings with mothers and care-givers. This would be an extension of other community health education activities, wherein they said that they could use similar methods (flip charts/ materials/ discussions/ question and answer mode) to provide information on child mental health issues.
- Identifying children with developmental disabilities and emotional and behaviour and providing referral.

In addition to the above two functions suggested by the PHC staff, they could also be trained to provide two types of inputs to families/ caregivers: i) early stimulation and home-based programs for all care-givers of children under five, to promote healthy physical and psychosocial development; ii) special inputs and home-based care programs and activities for mothers/ care-givers of premature babies and children with developmental disability. PHC staff could be supported to provide these inputs during the course of their home visits, through community outreach programs as well as in the PHC when children come to the clinic for nutrition and immunization services, during which time, they could also be screened for disability i.e. using a simple protocol or tool for disability screening and identification.

Note: At least during the initial phase of the project, PHC staff roles in child mental health will be limited to awareness creation and disability identification and basic intervention; they will not be trained in/ asked to provide first level responses to children (and families of children) with emotional and behaviour problems because: i) they do not do any exclusively direct work with children (unlike school teachers and anganwadi workers) and so do not appear oriented towards or highly interested in skill-based work with children; ii) they are already oriented towards care-giver counselling and awareness creation; and provision of disability-related inputs builds on these existing skills and experiences more directly. However, should the implementation of the project change some of their interests and orientation, their functions and training could be reviewed and extended to first-level response to children with emotional and behavioural problems as well.

#### 1.2. Medical Officers

# A. Interviews with Medical Officers

Findings & Analysis

# Knowledge and Awareness on Child and Adolescent Mental Health Risks in the Community

When asked what risk factors there were for children and adolescents, especially in vulnerable urban communities such as slums, three issues were most frequently mentioned by the MOs: alcoholism, malnutrition and lack of parental education and awareness. Some responses that were more generic, included poverty and unemployment as risk factors for child mental health issues.

While they were able to describe these as social issues, no mention was made of mental health issues resulting from them, even as the interviewer probed further and attempted to help the MO make the link between a social health issue and its mental health consequences to children. Here is an excerpt from one on the interviews:

Interviewer: You mentioned the issue of alcoholism. When parents get drunk, what impact do you think it has on the children?

Respondent: They get drunk and beat the children, use foul language.

Interviewer: And then what happens to the children?

Respondent: This is not a 1 day or 2 day problem for the kids...stronger kids will just be on their own and not care; weaker kids will become silent—they are so quiet, they don't tell their problems even when they come to the PHC—even if the problem is a physical health problem.

Interviewer: So what happens to these children when parents drink?

Respondent: Daily, if parents get drunk, children are not taken care of...they may be somewhat disturbed. Or some of them may be arrogant and angry. Or some are silent. Interviewer: These 3 groups of children you mention...each with different problems. Would you consider these as mental health issues?

Respondent: No. None of these groups have mental health problems...it is their way of life.

Another MO said: "...Alcoholism...but that is an issue among adults...you asked about children", also indicating that alcoholism is not considered to impact child mental health. However, one medical officer did make a link between alcoholism at home and children's mental health, in terms of scholastic performance: "There are also fights at home due to alcohol problems and this leads to mental health problems in children...due to which scholastic performance is low. So it is mainly education that is affected. Children will not be able to concentrate on studies and know the value of education..."

Lack of schooling among parents and (consequent) education and schooling problems was another issue commonly mentioned by the Mos. They explain that due to lack of parental awareness as well as poverty, many children in slums do not go to school or drop-out of school; many MOs felt that this happened because parents do not value education or give it the importance it requires: "Parents are also illiterate and not schooled, so they do not attach value of education. Therefore children will not be able to overcome slum problems." Thus, the schooling issue is linked to parental awareness and care-giving abilities. As one of the MOs said "To nurture children, there should be a proper home atmosphere, someone to send them to school regularly...there is no proper guidance for children..."

However, other responses acknowledged that lack of schooling and school drop-out happened because of poverty and unemployment as well as inadequate numbers of school accessible to these children. One MO whose catchment population includes a large slum area said that there were 3 to 4 private schools but only 1 government school in the area. He also spoke of how parents register children in schools until the ages of 10 or 11. He said that girls often discontinue school after 7<sup>th</sup> grade (or age 15) because of the community's preference for early marriage, soon after which they become pregnant and their lives are limited to being at home. He said that boys drop out of school by the age of 12 to 13 in order to support their families, and that they tend to be self-employed or working in factories at low wages. Their wages may range from Rs.50 to 80 per day and some children, such as case of a 17 year old boy, also a TB patient, and supporting his (single) mother are more vulnerable than others.

Another reason he provided for children dropping out of school was in the context of single mothers (either due to separation or widowhood), of whom there are several in some of the slum communities; "they have 2 to 3 children...who then have to start earning early. Many of these women choose to live in slum communities because the rents are more affordable...the average age of these single mothers is less than 35 years, and as young as 23-24 years." He thus believes that children from such single-mother families are more at risk of mental health issues than others.

One MO, also stated that children who go to anganwadis are at risk because of over-crowding. "At least 67 out of 70 anganwadi children I examined have lost their tympanic membrane due to ear infection. They will have minimum hearing loss...but no, it will not affect their mental health in any way. Overcrowding leads to ear infection...and this over-crowding will lead to conditions that will affect growth." Further, he said that the anganwadi children were at risk of mental health issues due to the 'harsh' communication styles of the anganwadi teachers: "They treat children harshly and even children start behaving in this way—fighting and quarrelling."

Nutrition was a frequently received response to questions about child mental health risks. The view stated by one MO was also echoed by some of the others: "Malnutrition is a problem. In order to be mentally fit, you have to be properly nourished". Or, as another MO said: "...Nutrition helps children under 5...micro and macro nutrients help in brain development...and therefore better mental health. Maximum brain development occurs until 2 years of age and extends until 5 years of age". One of the MOs spoke of how age and gender issues affect children's access to nutrition. According to him, when girls marry early and have frequent pregnancies, they have about 3 children (often under five) by the time they are 20 years of age, "so they cannot even raise one child properly; more attention may be paid to the younger child and the nutrition status of the older child may suffer...so the child may have attention-seeking disorders". He also said that male children were prioritized for nutrition and healthcare and hence, female children may be more at risk of mental health disorders.

Lack of awareness and negligence by parents was mentioned by many MOs, mostly in the context of lack of schooling or school drop-outs, as described above. One MO also talked about the lack of awareness amongst parents about child mental health issues: "The main problem is negligence of parents...they are not aware when to seek help. The needs have to

be identified by others such as link workers and anganwadi workers, and then onlythe children are brought to the PHC for help."

Only one of the MOs also mentioned domestic violence in the slums: "It is common in slums. But the impact of 17 to 18 year old girls, who are newly married, is more than older women of ages 35 to 40—who will be used to it by now. Young girls are shocked—because they are not used to it. At age 15 to 16, they have no decision-making power at home...they have repeated pregnancies and even if they are willing to abort, their husbands' family will not allow it." Concerns about early marriage and early/ repeated pregnancy (also linked to school drop-out) were also expressed by other MOs.

Two MOs mentioned migratory populations being more at risk. One said that people who shift from one slum to another or from one state to another, such as migrant labour, are more at risk of mental health problems, due to adjustment issues. However, the other MO spoke about migratory populations/ migrant labour residing in the slums as being more at risk of all health problems including mental health problems, particularly because of their beliefs in traditional/ religious healing methods and their poor health-seeking behaviour. "They are reluctant to come to us [the PHC] for immunization because they have some beliefs that the child will get paralyzed or not be able to walk if immunized. They generally go to religious healers for treatment. Slum populations also have these beliefs but migratory populations have a much higher level of these beliefs."

While more than one MO mentioned alcoholism as a risk factor for child mental health problems, most mentioned poor parental awareness and negligence and only one MO mentioned single mother and domestic violence as risk factors for child mental health.

#### Analysis

MOs' knowledge and awareness about CAMH issues appears to be extremely limited. Even within the area of disability, a sub-part of CAMH, the understanding is limited to identification of cerebral palsy. While mental retardation was also mentioned, it was more in the context of link workers being able to identify moderate to severe mental retardation—but more from a layman's perspective that the child appears abnormal. CAMH issues such as dissociative disorder and anxiety which often manifest in terms of physical symptoms are not identified. It is probable therefore that when children with such problems are received, their physical symptoms, which actually have no physical basis, are responded to with medical treatment, when in actual fact they require psychiatric assistance, including pharmacotherapy and counselling.

The medical officers reported that no training had been conducted for them or for other PHC staff on CAMH issues. Given her lack of knowledge and awareness on CAMH issues, one of the medical officers was unable to describe the type of training that should be made available to medical officers or to other PHC staff.

The other medical officer interviewed had some knowledge of psychiatric and neuro-psychiatric disorders—he was able to specifically name a few such as epilepsy, depression and attention deficiency hyperactive disorder (ADHD). However, his knowledge of signs and symptoms and types of treatments required for some of these disorders were extremely limited. For instance, when asked about signs and symptoms of ADHD, he said: "These children do not listen to their parents and are very mischievous" also mentioning that these

symptoms were common to young children between ages 3 and 4; on being asked about his response to such children (with probable ADHD), his response was: "We counsel the parents and the child...we tell the parents to try not scold and beat the child and to convince him with good words. We counsel the child by telling him to listen to his parents, concentrate on his studies and involve himself in playing games". Further, he spoke about the lack of need to refer children with ADHD issues: "No, we do not refer these cases. We try to counsel them here at the PHC...because we do not refer certain age groups...because such symptoms are common to this age group and they will be become alright on their own". His responses thus indicate inadequate knowledge about symptoms of even childhood mental health disorders that he has awareness about, and consequently the lack of knowledge about treatement and referral needs.

Neither the Medical Officers nor the other PHC staff have received any training or inputs on CAMH issues. Consequently, at present their knowledge and skills in the area are non-existent. That they are able to identify cerebral palsy and severe mental retardation is not an indication of knowledge or skill; it is reflective only of the ability that most lay persons have to recognize some very obvious abnormality in children or others. Further, this ability to perceive abnormality is limited to lack of or delays in gross motor skill development in children; no details on other developmental abnormalities or behavioural anomalies were described. Thus, it is evident that training programs on CAMH issues are required, not only for field staff such as link workers but also for cadres such as medical officers, who while doing clinical work at the PHC should be able to at least recognize and identify developmental disabilities and behavioural anomalies in children; early identification will enable appropriate referral and early intervention for the children and their families.

# Extent and Type of Child & Adolescent Mental Health Cases Received at PHCs

Most MOs report that child mental health cases are not seen/ received at the PHC. Most people come to the PHC for physical health problems ranging from fever to TB and ARTIs. When asked about disability, MOs reported that they hardly receive children with developmental disability at the PHC; some reported that they may have seen two to three cases of autism and cerebral palsy over a period of about six months. One MO reported seeing ADHD cases from time to time and that these were children usually 3 to 4 years old, identified as having ADHD because they 'do not listen to their parents and are very mischievous'. Other Mos said that most cases of disability were identified during the general health check-ups conducted for anganwadi children and during polio campaigns. It was also observed by one MO that disability cases are often found amongst children of migrant labour from Andhra Pradesh and Tamil Nadu.

All except one MO said that the PHC did not receive cases of children with emotional and behaviour problems. In this regard, one MO said "maybe we do not spend much time with patients...we need a rapport to get to understand emotional and behaviour problems [in children]". She stated that at the PHC patients are seen for a very brief period of time and not necessarily more than once—unlike her medical practice at a nearby orphanage where she has been practising for a long period of time and where she therefore knows the children and their problems.

Only one medical officer reported receiving cases of emotional problems, namely depression, mostly in 15 to 16 year olds, who are brought by their parents because of sleep

and appetite problems as well as lack of concentration in studies (the last being the main concern of parents).

The issue of PHCs not receiving child mental health cases appears to also be related, according to some MOs, to communities' health seeking behaviours with regard to disability and mental health problems. One MO maintains that people do not lack awareness—"people are already aware of disabilities in their children—when they come for immunization, they say that their child is not looking at them or that their child is not growing like the sibling...and they know where to go and what to do...they are very good at medical shopping."

This MO also spoke of the adolescent clinic (Sneha Clinic) that PHCs have been running for the past year, a BBMP program, in which the clinic runs from 2 to 4 pm every Thursday. However, she (and other MOs) reported that adolescents do not access this clinic, despite having provided information about it in schools. She feels that in general, children from middle and upper middle socio-economic groups do not access PHC services—they usually go to private hospitals. In recent times, she believes that lower socio-economic groups also visit private healthcare facilities versus government facilities as they have 'no faith in government staff and facilities;' and that if they do not visit private facilities then they visit traditional healers and 'quacks'. Further, she said that in urban areas, unlike in rural areas, people have a choice of health facilities; in rural areas, they have little choice but to seek healthcare (whatever the problem) at PHCs. These are also reasons why PHCs do not receive

MOs also said that children with disability were discriminated against by their families, in terms of food and education. There are hardly any special schools in the area, and when some families send their disabled children to normal school; in one case, a mother who tried hard to send her child to normal school had to finally stop because other children constantly teased this child. Such social stigma and discrimination prevent families from accessing care for their disabled children. Further, according to some MOs, even those who go to tertiary care facilities directly, for disability/ mental health care go only when the problem is at a level where it affects the family's daily life i.e. when they are unable to cope with or mange the child-- "Otherwise, they do not consider these issues to be mental health issues...due to lack of awareness, poor literacy...and they do not want to accept that it is a problem."

#### **Analysis**

It appears that people generally do not seek care for child mental health problems at PHCs, not even if children have disabilities or emotional/ behaviour problems that are clearly visible or very obvious to families. Reasons range from communities' awareness of mental health issues to social stigma associated with disability and mental health problems, due to which families do not access care anywhere. However, given that many families seek mental health care for their children, at a tertiary care facility such as NIMHANS, it is apparent that social stigma does not always operate; and that people do not seek care at the PHC because they do not view it as a place where mental health care would be available—and this is true because PHC staff are not trained in mental health care and generally do not provide it. This is corroborated by the MO's understanding that urban communities, even those from lower socio-economic strata, tend to seek care at private healthcare facilities or tertiary care/ specialized care facilities.

While MOs may be right in thinking that many families can recognize that their child has a disability, especially if it is an obviously visible one, the concept of awareness is broader than mere recognition of a problem. At a first level, awareness entails not only identification but also an understanding of the nature of the disability/ problem, the need to seek care, and places to seek care; at a higher level, awareness entails understanding the treatment options available, including the prognosis and possibilities of cure--which for instance families with children with disabilities frequently do not understand thereby expecting drugs to 'cure' the disability. Thus, MOs need to be more nuanced in their understanding of community perceptions of mental health and disability, so that they can address the awareness issue by providing more detailed information during consultation.

From the responses of the MOs it also appears that their knowledge of child mental health problems is low. In fact, many of them did not think of disability as being a child mental health issue until pointedly asked about it. As a result, the types of child mental health cases identified may be limited as may be the number of cases.

# Screening and Referral Services for Child & Adolescent Mental Health

All MOs reported that no basic screening tools or checklists for child and adolescent mental health exist. Currently, there are screening forms/ check lists only for immunization and nutrition. It is evident that MOs identify children occasionally, when they recognize symptoms of certain developmental disability (such as ADHD and autism or cerebral palsy, as they mention) or mental health problems (depression is the only one mentioned and that too only by one MO).

With regard to identification of child mental health problems, one MO, "some diseases are easy to identify—such as disability…but the problem is diseases that are borderline—these are not so easy to identify. This second type [borderline], you need to ask school teachers to help you because they are with the children the whole day…but we see children for a very short time, short contact period—so we can know only so much." Thus, contact time was given as a reason for not being able to identify children with mental health problems.

When MOs identify some children with child mental health problems, such as developmental disability, some MOs do not mention referral at all, while some others state that they refer them to Sanjay Gandhi Hospital, Indira Gandhi Hospital, Victoria Hospital or to NIMHANS. The choice of hospital sometimes depends also on whether the MO has a personal contact there. Direct Referrals to NIMHANS are not often made because 'people panic and feel that it is a very serious issue. Therefore, we refer them elsewhere first...and then come back here with an opinion. We may, at that time, refer them to NIMHANS—or the place we refer them to may already have referred them to NIMHANS'. Another reason for not referring children to NIMHANS was 'I just think it is very busy, so I don't refer there' although on being asked if the MO knew of families not being assisted at NIMHANS (due to crowdedness), he had had no such experience i.e. this was his assumption.

Although some MOs are aware of psychiatrists' presence in the above-mentioned hospitals, some MOs were not so clear about where the referral within these hospitals was to be made. In one instance, a child that the MO diagnosed with autism was referred to an ENT at Victoria Hospital, and when asked why, she said that they (the ENT) does the relevant tests and gets a neurology opinion if necessary, following which a further referral may be made to NIMHANS.

There is no follow up on the referral and so it is not known how many families actually sought specialized care when advised by the MOs/ PHCs. Migrant communities generally do not seek treatment even if referred because they do not stay long in a place i.e. they often return to their home towns and villages.

Only one MOs mentioned 'counselling' children whom he identified with problems—'we counsel them about depression but no drugs are given because we have no drug supply of this type'. In case of ADHD children, he said 'we counsel the parents and the child...we tell the parents to try not to scold and beat the child and to convince him with good words. We counsel the child by telling him to listen to his parents, concentrate on his studies and involve himself in playing games.' He also said that they tend not to refer children identified with ADHD: "we try to counsel them here at the PHC...because we do not refer certain age groups...because such symptoms are common to this age group and they will become alright on their own."

### Analysis

That there are no screening tools and check lists account for why there is no systematic identification of children with mental health problems. Currently, it appears that some children are identified randomly by MOs, based on their knowledge and observations. Their knowledge of child mental health, as is evident from some of the counselling inputs provided to children and families is far from adequate. The ADHD counselling issue and reason for not referring is a clear indication of a lack of knowledge or understanding about childhood mental disorders and developmental disabilities.

While contact time with the patient/ child does influence how much a physician can glean about mental health issues, the purpose of screening is not the same as extensive observation or even detailed evaluation. A screening tool, through use of a symptom checklist, would enable the MO to rapidly elicit information from the child and family about certain mental health issues, to make a decision about whether the child has a problem and broadly of what nature this problem is. The MOs' siting contact time with the patient as a limitation in identification of child mental health issues reflects a lack of understanding of screening tools and their purpose (at least with regard to their use in mental health).

Referral patterns are also ad hoc. There is no standard protocol about where referrals should be made, how to direct the family there, including explaining them the nature of the child's problem and the need for referral services. Unless there are standardized tools for screening and protocols for referral, children with mental health disorders will neither be identified nor will they receive appropriate assistance.

# Scope for Incorporation of Child & Adolescent Mental Health Services into Primary Healthcare

Most MOs agreed that child mental health services should be incorporated into primary healthcare. Some articulated various challenges this would entail (detailed in the next subsection). Few MOs were able to clearly articulate ways in which child mental health services could be incorporated into PHC.

Only one MO was able to explain how early identification, awareness and follow up should be done at the community level. He explained how for nutritional problems, when some children are referred to government hospitals for treatment, families do not take them due to reasons such as having other children to care for. Therefore, the issue requires continuous follow up, he said, and it cannot be a one-off intervention. It would be similar, he felt, for child mental health issues, recommending that problems should not only be identified and referred but that link workers would need to follow up intensively to ensure that children/ families had sought care. He said that the other major issue for community child mental health, at PHC level, was awareness. He suggested that awareness about child development could be done through *Shree Shakti Sanghas;* and that later it could be done through the *Rogi Arogya Samithis* (RAS) which will be set up under the National Urban Health Mission (NUHM). Each RAS will comprise of ten people from the community and their objective will be to create public health awareness, in coordination with the PHC. Under the NUHM, there are also plans to increase the numbers of ASHA workers (community health workers with functions very similar to link workers) and they could also be involved in community awareness creation.

Most MOs, however, did not have similar ideas or suggestions and were at a loss when asked how mental health services could be incorporated at PHC level. At best, they suggested involving the link workers in screening and identification processes. One MO even said "within the clinic, you can just do an orientation for MOs...you cannot do much...because we do not get cases. So, it is mainly for guiding our field staff."

Lack of awareness on child development issues is reflected by one MO seemed to be relatively poorer said that he was not sure that there was scope for disability work in anganwadis: "it is too early to start mental health for them...unless they have some pathological disorder. Some children start talking only after 2.5 years..." When further asked whether he would consider this a mental health issue, he said: "No, below 3 years, I do not consider this a problem."

#### **Analysis**

Given that MOs' knowledge and awareness of child mental health issues is poor, unsurprisingly, they were unable to articulate the scope for inclusion of basic child and adolescent services at PHC level. They acknowledge the need for it but seem unable to think about how PHC staff could be involved in provision of basic levels of child and adolescent mental health, except for some suggestions that screening and referral work as well as awareness campaigns should be conducted by the link workers. There is a strong push for community versus clinic-based services as all MOs felt that community child mental health services should be largely implemented by link workers.

It is true that a strongly community-based approach, involving link workers, through campaigns and home visits would enable community awareness on child mental health issues and identification/ referral of children with mental health problems. However, this does not negate the role of the clinic or PHC cenre; in fact, it means that the PHC (and within that the MOs) need to play a strong role in screening and identification and strengthening the activities of the mental health clinic and the Sneha clinic through provision of primary and secondary levels of care. Statements such as there requiring to be just an orientation for MOs because no child mental health cases appear in the PHC (as of now) shows a lack of vision and is also indicative of an attitude—that of not wanting to participate in service provision relating to child mental health. Indeed, from the push towards relegating all community child mental work to link workers, it seems like the attitude of most MOs is to disengage or do minimum work. This analysis is corroborated by findings from a workshop

(proceedings documented in subsequent sub-sections) conducted with MOs, to make decisions on next steps and implementation of community child mental health activities at PHC level.

# Perceived Challenges in Incorporation of Child Mental Health Issues into PHC Services

One MO in particular spoke extensively about the challenges in incorporating child mental health issues into primary health care with regard to the link workers' role in it. Her first concern was that 'link workers do not have the capacity. They are SSLC drop-outs...if it is too complicated, they cannot do the work. They can only identify fever and diarrhoea, not mental health issues.'

Another concern she raised was the existing job dissatisfaction experienced by link workers due to low salaries as well as late payment of salaries; the BBMP also hires agencies to pay their salaries but due to middleman corruption, a cut of the salaries is often taken by them and the link workers get less than they are meant to. As a result, link workers' motivation levels are low and their drop-out rate tends to be high.

The third concern raised by the MO was that the burden of work on link workers already high: 'They work from 9 am to 4 pm. Between 9 am and 2 pm, they have to be in the field and from 2 to 4 pm, they have to be at the center and do a lot of data entry and register filling. So, adding one more responsibility [child mental health] may be difficult.'

Her last concern was regarding the responses of the community to the link workers and how people do not trust the latter: 'They feel that the link workers get some special incentive from the government to do the work. They do not trust them.' She pointed out that these trust issues have to do with the fact that in an urban area, unlike in a rural one, link workers do not live in the community they work in, so 'there is no rapport with the community.'

Challenges relating to the community-based work were also highlighted by one of the health assistants who spoke about a community-based mental health program on the specific issue of domestic violence. The health assistant was asked (by the implementing agency) to record and report any incident of domestic violence in the community, so that counselling services could then be provided by the agency. 'But this type of recording and reporting was very difficult for me. I live in this community and so do some link workers. When domestic violence occurred, women were unwilling for their problem to be reported...the community did not cooperate, they did not want us to report this type of issue.' Her concerns extended to her family, particularly her daughters, whom she feared would be harmed should there be anger against her for reporting issues about violence. 'So, I did not want to be involved and told them after one month that it is not possible for me to do this,' she said.

When other MOs were asked about over-burdening of staff and other anticipated challenges in incorporating child mental health into PHC work, they also agreed. However, many MOs also mentioned the initiation of the National Urban Health Mission and how it envisaged an increased number of PHC staff. 'Instead of 1 doctor, there will be 3...instead of 1 ANM, there will be 3 and 8 to 12 link workers instead of 4', said one MO. Some also felt that link workers could incorporate child mental health issues into their work also because they were doing home visits (50 per day) in any case, and that if there is additional work, they could cover

fewer houses per day. Yet other MOs were unable to anticipate any challenges at all, should child mental health work be included into PHC activities.

### Analysis

The challenges raised, with regard to link workers' burden of work, low pay and poor motivations must serve as important considerations in developing child mental health programs at PHC level. In the light of how MOs see most child mental health activities as being conducted by link workers in the community (and to a much lesser extent by themselves within the clinic), these considerations would be critical to the implementation of community-based child mental health care.

The challenges with regard to community presence of the link workers are complex. While link workers living in the community may serve to build rapport and trust in the community, it could also make it difficult for them to do sensitive work. While domestic violence reporting/referral has different implications, some issues may be common to child mental health—such as experiences of stigma and discrimination experienced by the child and family. Also, given that child mental health will include (though not limited to) addressing issues of child physical and sexual abuse/violence, lessons learnt from other community-based projects such as the one described by the health assistant, would be well-worth considering. This learning may be used in the design of especially sensitive child mental health interventions pertaining to violence and abuse i.e. decisions about levels of programming, public awareness versus individual interventions need to be made. Where individual children and families are targeted due to occurrence of incident, interventions will require to be designed in ways that are child-sensitive; this includes the best interests of the child in ways that do not publicize individual/family trauma and thereby exacerbate stigma and discrimination.

#### The Need for Training and Capacity Building

The MOs reported that none of the PHC staff, including medical officers, health assistants and link workers, had received any training or orientation on child mental health issues. When asked whether it would be useful, all MOs agreed that it would be useful. When asked about which PHC staff should be trained, all of them tended to mention link workers are a priority for training because 'link workers go to the field and they can counsel or refer correctly if they have the knowledge and training to do so' and 'they go to the households to do the survey...so if they pick up on cases, they can report them'. They acknowledged that MOs and health assistants also needed to be trained but the reasons were less clearly stated. Some MOs stated that they required training in order to be able to guide the link workers while some who also demonstrated less awareness about child mental health issues gave reasons such as 'there is no harm in learning new things'. The MOs were also relatively unsure of the types of child mental health issues PHC staff required to be trained in. One of them mentioned 'basic psychiatric illness, substance abuse, ADHD and mental retardation' but others were not able to articulate any particulars.

#### Analysis

The unequivocal view that link workers should be prioritized for training in child mental health issues reflects that: i) child mental health work should be done largely in the community and therefore most actively involve the link workers; ii) consequently, this means that the clinic (and therefore the medical officers and health assistants) will play a less active role in child mental health; iii) even if the PHC role in child mental health is limited to screening and

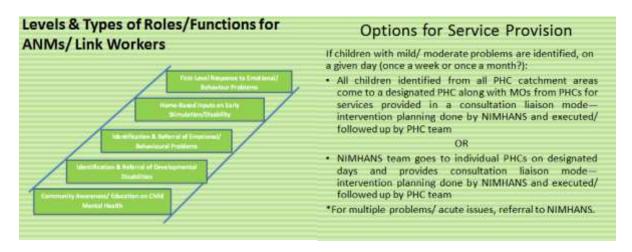
referral, the bulk of this responsibility would be undertaken by the link workers—since the medical officers were not able to clearly articulate how the screening and referral process would work in ways that involved the clinic itself and their inputs.

Agreeing that MOs should be trained more for guidance purposes rather than being actively involved in child mental health screening/ referral work is perhaps an extension of how they view their roles in other areas related to health work i.e. it appears that they rarely visit the community unless they have particular tasks such as anganwadi check-ups. This is corroborated by the fact that when asked for basic information on the PHC catchment area (no. of anganwadis, schools, slums etc), most MOs had to call upon the health assistants and link workers to provide it.

As such, the PHC, at least in urban areas, does not appear to be viewed as part of community health infrastructure; there seems to be a division in their minds between primary health care provided within the clinic and community care as opposed to seeing it as a continuum. The MOs perceive it to be facility that provides clinical care, especially acute care and other government programs such as immunization, malnutrition care, and MCH services. However, to look at the PHC as a larger space where programs on health awareness, child development, parenting etc can be carried out is not seen as a role for the PHCs, not even as an extension of MCH and other child health related services. Their lack of knowledge is child mental health made it difficult for them to articulate the types of issues staff training should include.

### **B. Workshop for Medical Officers**

Based on the findings of the needs assessment, various options were presented to the Medical Officers of the PHCs, for incorporation of child mental health into the PHC system. Broadly, they were ways in which ANMs and link workers could be involved in child mental health awareness, early identification/ referral and response, and ways in which a service component could be incorporated at a primary/ secondary level (see boxes below).



Medical Officers did not believe that it would be possible to involve ANMs and link workers in addressing community child mental health issues, not even at the basic levels of awareness creation and education of care givers. The reasons given for this were: i) these cadres of PHC staff are already extremely over-loaded with other community health programs they need to implement; ii) their salaries are seldome paid on time (they are usually at least 3 to 4 months late each time); iii) they are accustomed to referring cases to the PHCs only if they

are paid incentives; iv) in almost all PHCs there is severe shortage of staff/ human resources i.e. 1 link worker should be serving 2,500 population, she serves about 10,000 population; since there are PHCs that need to have at least 8 link workers (due to the catchment population size), there are only 4 and where there need to be about 4 ANMs, there is only one, there is a staff shortage of about 50%. While the National Urban Health Mission has made provisions for increased link workers, these increased staff numbers have not been met in the PHCs as yet. Consequently, according to the MOs, it would not be feasible at this point to involve ANMs and link workers in community child mental health interventions to the level and extent envisaged by the upcoming community child mental health project of Dept. of Child Psychiatry, NIMHANS.

What is possible for now, according to the MOs, is the service provision component. They are willing for the NIMHANS team to visit individual PHCs on designated days (certain number of times per month) and provide services through consultation liaison mode— i.e. with intervention planning done by NIMHANS and executed/ followed up by PHC team. The children from the community (respective PHC catchment areas) will be referred by School Health Teams (through their screening work at schools) and NIMHANS project staff (through their presence in the community). Thus, for the present, the upcoming community child mental project of NIMHANS will work in collaboration with the Dept. of Health/ PHCs as follows:

- Provide services to to children identified with behavioural/ emotional problems and developmental disabilities, through consultation liaison mode.
- Develop screening tools for use with children seeking other health assistance in the PHC i.e. so that MOs and ANMs can screen children who might be presenting for other medical complaints and thereby identify mental health issues also.
- Develop screening tools for School Health Teams who work in collaboration with the PHCs and can therefore refer children with mental health problems to the consultation liasion services.
- Project staff will maintain some community presence through/ along with link workers
  of the PHCs and conduct awareness/ education sessions (using health education
  materials developed for this purpose) for community/ caregivers along with link
  workers i.e. the onus will be on the project staff to take the lead and link workers will
  only be expected to be present and assist in there sessions.

Further, the project will support PHCs to re-vitalize Sneha Clinics, which are weekly clinics run by many PHCs to promote adolescent health. Currently, while many PHCs run these clinics, as per the Health Department's mandate, the MOs report that hardly any adolescents access care at this clinic. The lack of utilization of this clinic's service is attributed to the community's 'lack of awareness'. But it is not clear whether this lack of awareness is about the existence of the Sneha Clinics, or about the types of services that adolescents may avail of there (what exactly do 'adolescent health services' pertain to?). Also, the MOs themselves are not sure about the guidelines for Sneha clinics, what the content of the services should be, and have not received any training on this issue, although they continue to provide the department with reports as required. To begin with, NIMHANS's community child mental health project will plan training programs on adolescent mental health, so that the Mos can implement the Sneha Clinic services more effectively.

Contrary to what was originally envisaged by NIMHANS's community child mental project, it is now to begin with a service provision compoment —versus a community awarness/ education appraoch, followed by identification/ referral and then service provision or at least for community awareness/ education and early identification and referral through active link worker participation to occur in concurrence with service provision. Such an approach was necessitated by the PHC systems' administrative gaps and limitations, which do not allow link workers to take on child mental health activities as part of incorporation of child mental health into primary healthcare services/ facilities. However, it is hoped that by starting with a service provision approach, child mental health issues will gradually gain visibility in (vulnerable) communities and also draw the interest of the link workers through their intial limited involvement in the issue along with project staff.

#### 1.3. RBSK School Health Teams

Two focus group discussions were held with the RBSK school health teams serving government and aided schools in the catchment areas of the selected PHCs. Subsequently, an awareness workshop was held for 21 doctors from these two teams, as well as those from other school health teams, serving other zones (north/ east/ west) in Bangalore Urban. (Refer to annexe 3 for RBSK teams participating in the workshop).

# A. Focus Group Discussion

# **Role and Function**

School health teams (SHTs) are a recent initiative, as part of the RBSK program. Originally under the National Rural Health Mission (NRHM), it functioned only in rural areas, but it has now been extended to the National Urban Health Mission programs and serves anganwadis and government and aided schools (including BBMP schools) in urban areas as well.

Anganwadis are covered by the school health teams once every 6 months, approximately twice a year (they are also covered by PHCs every 2 months). Each school is visited by the school health team once a year. (Previously, schools used to be covered by the PHC but this is no longer so with the arrival of the new school health teams under RBSK).

School health teams conduct physical examinations for children, screening them for basic health problems and the conditions listed under the RBSK. The RBSK envisages screening children between ages 0 and 18 years for the 4 Ds: Defects at birth, Diseases, Deficiencies and Development Delays including Disabilities. The team's function is limited to screening and referral i.e. no medical interventions are directly provided by the team.

For Bangalore South Zone, there are two school health teams that have been functioning for the last 4 months. Team A covers schools in Jayanagar, BTM Layout and Padmanabnagar; Team B covers schools in Basvangudi, Vijaynagar and Chikpet. Each team comprises of 3 doctors, a staff nurse and an optician; these staff are recruited under the National Urban/Rural Health Mission but posted under the BBMP. While there are currently 4 school health teams for Bangalore Urban, for the purposes of this project, focus group discussions with the doctors from the two teams in Bangalore South Zone were held.

Findings & Analysis

# a) Magnitude and Types of Child Mental Health Disorder Identified

According to one of the SHTs, at least 2 in every 100 children have some sort of problem—like ADHD, learning disability or autism. Autistic children tend to be under treatment and

some teachers are also trained in autism issues). They reported that out of 1,200 children they see in a month, they may find about 10 children with problems. They usually have 'major issues such as Attention Deficiency Hyperactive Disorder (ADHD), they are very aggressive, and have cognitive problems or disability'. This team also mentioned 'children who do not talk, do not mingle with other children or respond only to one teacher, if at all' and that they also refer these types of children. Further, they spoke about 'normal children' who have concentration problems at school because 'their parents are living apart, ' have money problems...the child is not able to dress properly, the child is criticized by others and the child may have a complex...so the child is not able to concentrate in class'.

The other SHT mentioned delayed milestones (seen more commonly in anganwadi children), cognitive problems and behaviour issues, of which they said that the most commonly incident problem was behaviour problems. They describe hyperactivity, poor concentration, poor academics, slow learners, speech delay, and specific learning disabilities as behaviour problems. They said that autism and mental retardation were not commonly seen in schools, because schools were unlikely to admit such children. They also said that all mental health problems were considered to be neurological.

# Analysis

There can be no conclusive evidence on the magnitude of child mental health problems, based even on approximations by the school health team. As per the team's identification processes, 10 out of 1,200 children have a mental health problem i.e. 0.8% of children screened have a mental health issue. This finding and its service implications needs to be seen in the light of existing data on child mental health conditions. For example, the results of the 2005 ICMR-funded study done in urban and rural areas of Bangalore. According to this study, 12.5 per cent among children aged 0-16 years have psychiatric health issues. The psychiatric morbidity among 0-3 year old children was 13.8 per cent with the most common diagnoses being breath holding spells, pica, behaviour disorder NOS, expressive language disorder and mental retardation. The prevalence rate in the 4-16 year old children was 12.0 per cent. Enuresis, specific phobia, hyperkinetic disorders, stuttering and oppositional defiant disorder were the most frequent diagnoses. When impairment associated with the disorder was assessed, significant disability was found in 5.3 per cent of the 4-16 year group. 10 While the ICMR study is a community-based study and the RBSK findings are school-based, the marked difference in the prevalence of child mental health conditions needs to be interpreted and understood.

The reason for the identification of very low numbers of children with mental health problems by the school health teams are primarily: i) their knowledge of child mental health issues is relatively limited or not detailed enough, especially in the area of childhood emotional disorders, to be able to identify many disorders; for instance, the identification of problems such as enuresis, specific phobias, early childhood disorders such as pica or breath holding spells entail greater knowledge about them; ii) there is no systematic screening format that would enable them to pick up on a wider range of child mental health problems.

That said, the school health team doctors appear to have a much wider knowledge of child mental health problems than PHC medical officers as they mention identifying issues such

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<sup>&</sup>lt;sup>10</sup> Srinath, S, Girimaji, S.C,Gururaj, G, Seshadri, S, Subbakrishna, D.K, Bhola, P, Kumar, N (2005). Epidemiological study of child & adolescent psychiatric disorders in urban & rural areas of Bangalore, India in Indian J Med Res 122, July 2005, pp 67-79

as disability, behaviour problems, academic problems. While they do not use the term 'emotional problems', the description (above) of the child with concentration problems as a result of family/ home issues indicates some understanding of emotional issues in children and how they are a part of child mental health. One of the teams also appears to make a distinction between externalizing disorders (aggression) versus internalizing disorders (the child that does not mingle with anyone).

The most frequently mentioned problem when asked about types of child mental health, for schools health team staff, was also ADHD. Given that there is no screening or check-list used to make this (provisional) diagnosis, whether ADHD is really a common child mental health problem is hard to ascertain. Again, given the relatively limited knowledge on child mental health disorders, especially pertaining to their symptoms and the process of diagnosis, we may safely assume that other child mental health problems probably exist but are not identified.

# b) Process of Identification of Child Mental Health Disorders

The SHTs said that they use 'observation and interaction' methods to identify children with mental health problems. 'We can make out that some kids have a problem—like speech. And then we ask further questions...especially in case of any disabilities we see', they said. Both SHTs said that they ask class teachers about children's problems. Questions to the teacher, such as 'who are the slow learners? Do you know who has epilepsy problems?' enable them to identify children with disorders. 'While doing the regular examination, if in doubt we ask the child—they cannot always tell us and they are scared because we are doctors...so we ask the teachers', said one of the teams. One team also mentioned other children i.e. the child's peers as a source of information. 'Children sitting next to the concerned child tell us a lot—like 'he does not know how to write'.

Both teams said that there were no screening tools for mental health problems. 'We just do a basic diagnosis—based on the symptoms we can see…based on our medical knowledge.' When asked about instances where there might be no visible indication of a problem, the SHT staff acknowledged that 'sure, these children would be missed' and 'our diagnosis is not perfect…we have a maximum of 5 to 10 minutes with a child and some extra time if we have a doubt.' The 'yellow card' that is used to record information about each child, only contains guidance for physical parameters such as general appearance, eye, ear, cardiac problems; there are no provisions on the card to record information about the child's mental health. However, where there are mental health problems, the SHT staff record it on the card anyway.

# Analysis

It appears, that in the absence of a screening tool, the SHTs are reliant on a combination of 3 factors for identification of child mental health problems: i) their medical knowledge, ii) observation and physical examination; iii) creativity and initiative, mainly through eliciting information from teachers and other children.

As discussed in the first sub-section, their medical knowledge with regard to child psychiatry although definitely superior to other cadres of PHC staff is not extensive. This restricts their ability to identify a full range of child mental health problems that they may encounter. A screening tool would help alleviate this problem because not only would their knowledge and

awareness automatically increase through the use of a screening tool but systematic screening would ensure that children with problems are not missed out.

The lack of a screening tool also means that the SHTs are almost fully reliant on their observation and physical examinations. While these methods are useful, they limit diagnosis to physical disability or largely 'visible' child mental health problems, thereby leaving out a whole gamut of disorders that are emotional, behavioural or academic-related. A screening tool would overcome some of this problem by allowing for eliciting of information that was not purely observational.

The SHTs creativity and initiative is commendable in that they take a keen interest in moving beyond the yellow card parameters to ask persons other than the concerned child for information i.e. teachers and other children. Asking teachers is a useful and important method of identifying children with academic, behavioural and related emotional problems. However, teachers' knowledge cannot be relied on at all times (there is the issue of their limited knowledge of child mental health issues), it may not be uniform across individuals and schools, and lastly, it is likely to be biased towards identifying cognitive, academic and certain behaviour problems i.e. it is less likely to be help identify internalizing disorders and emotional problems. Thus, teachers' knowledge is valuable and can certainly be one of the ways in which children with disorders can be identified, but cannot be used as a substitute for a screening tool.

Lastly, the utility of methods such as eliciting information from a child's peers is a debatable one. Encouraging other children to talk about a particular child's problems will have adverse impact on peer relationships and exacerbate problems of stigma and discrimination for children with mental health problems. This method of enquiry is therefore not a suitable one for identifying children with mental health problems.

#### c) Referral and Follow Up

## Facilities and Services Used for Referral

The health facilities and services where children are referred for treatment of child mental health disorders varied considerably between the two school health teams. One team said that they always referred children with mental health problems to the PHC. Their reason cited by them for this was the stigma attached to seeking mental health services at institutions such as NIMHANS. They believe that 'parents do not want to take children to NIMHANS. When we refer them, they may say ok to the team but they do not follow up with the referral. They feel: 'what will people think?" On being asked about other reasons for selecting the PHC as the place of referral, this team also said: 'PHC is the ideal space...the link workers are here, everyone knows it...and people come here. The link workers are known to schools also because they go to government schools for immunization'.

The other SHT, however, reported that in case of general/ common health issues such as respiratory infections, children are referred to the PHC. In case of particular issues, they are referred to specialized services: for all neurological issues, they are referred to NIMHANS; for Cardiac problems to Jaydeva and in case of eye problems, to Minto Hospital. Children are also referred to Indra Gandhi Hospital, Vani Vilas Hospital, Bowring Institute and Victoria hospital for a variety of health issues. When a child is screened and found to have a problem, the SHT staff talk to the school/ teacher and to the parents if possible, or tell the

teacher to tell the parents to take the child. The referral is noted in the yellow card used to record the child's information.

# Implementation of Referral and Follow-Up by Families: Barriers and Facilitators

Both SHTs expressed several concerns about children/families obtaining the referral services recommended after the SHT screening. Physical health issues such as heart problems, when referred are speedily attended to by families, whether at PHCs or specialized services. But they say that parents are not likely to take children for specialized services when referred for mental health issues. The reasons range from the stigma attached to availing of mental health services (as described above) to affordability and transportation issues and parental acceptance:

Some parents cannot afford it. In Indira Gandhi Hospital, for instance, they ask for many scans etc and some of these parents have no fee for transportation.

'... we had a case of a child with ADHD but the mother simply would not accept the issue'.

According to the SHTs, educated parents are more likely to take children to specialized mental health services but uneducated parents usually do not take their children for such services. The latter group's concerns are: 'how can we take the children? How will we talk to the doctors?'

The SHTs have also often observed that children living with grandparents i.e. with parents living separately/ elsewhere are less likely to follow through with recommended referrals. They feel that it is because grandparents are not able to manage these aspects of child care i.e. availing of special services for child mental health, that they 'have no information on what to do and where to go or how to do'. The SHTs have also observed that this happens more in the case of children with disabilities and neuro-motor problems, and that these children are more likely to be sent to live with grandparents.

'Teachers in government schools do care...they know that these kids are not cared for at home. In every school, there is at least one teacher who is very interested in children's issues and comfortable with parents and ready to convince parents. In one school, there was a headmistress who was ready to take leave and take the child to NIMHANS. The principals know who the interested teachers are...and the school could arrange to take the kids if the place is nearby—like the PHC', said one of the teams, to explain that teachers are not only a reliable source of information at the time of screening but are also willing to go the extra mile and take children to treatment facilities.

# Where and How to Arrange for Referral Services

According to the teams, 'if the teacher is very caring, they may go once and take medicines. But still, there will be no follow up'. The issue of not only availing of the referral but of subsequent follow-ups is of considerable concern to the SHT. Based on the discussions about barriers and facilitators to implementing the SHTs' referral and follow up instructions, the SHTs made some suggestions and recommendations.

One team said: 'If we can arrange transport—like a van once a month, we can collect all these children and take them to NIMHANS for treatment—it would make a big difference. At least for the first time, we could bring them with the link workers'. This recommendation was also made in the light of problems relating to cost and affordability issues, which also affect the means for paying for transportation to tertiary care facilities.

After initially recommending that transport be organized periodically, to take children to the tertiary care facility, the team thought through this idea of getting children to access mental health services further and said: 'What would be helpful is if we could bring these children to the PHC and the NIMHANS staff could come to the PHC once a month or so and see them. If the parents/ children come and see you at the PHC, at least once, they may trust you...and then be willing to come to NIMHANS for further inputs. The issue is to convince them to come to NIMHANS. Getting them to come to NIMHANS is difficult because of the stigma attached. So, the schools in this area can be grouped under 1 PHC and the children brought to the PHC'.

Another recommendation with regard to the PHCs role in referral and follow up was that initially, after referral, the child should go for the first consultation to the specialist/ higher centres so that he/she can get proper treatment; but later, the child should return to the PHC for further follow up. When it was pointed out that subsequent follow-ups would also require revisions in medication/dosage and further therapeutic inputs, all of which may be difficult for the PHC staff to provide at their current level of child mental health knowledge and skills, the team agreed that there needed to be training for PHC staff in order to be able to provide such inputs during follow-ups.

A recommendation related to the issue of families, especially less educated families intimidated by the systems and processes in large tertiary care facilities was to have a designated point of contact from the tertiary healthcare facilities. This contact would be made available to the families through SHTs, so that treatment processes at the facility could be set up in ways suitable to the family. "We need a contact person at NIMHANS…so that parents can call them and find out where to go and how to go, what to do. This would help. Otherwise, they do not know how to negotiate the system".

#### The Need for Record Keeping and Referral Forms

Both teams, despite their difference in their approach to referral i.e. places of referral, agree that systematic referral and follow up is very important for child mental health issues and that the requisite forms should be developed for record-keeping and follow up purposes. Since the school health team initiative is a relatively new one and the teams only recently started work, as of now no formal formats/ forms for referral and follow up exist. While one team talked of the need for referral and record-keeping forms, the other team has taken the initiative to develop their own forms for referral and record-keeping. They maintain a form for each school and this contains school details, number of children referred, names of children referred including for what type of problems. The team said that they also provide the medical officer at the PHC with this list of referred children—because the children are referred to the PHC as a first point of contact, by this team (unlike the other team who refer children to specialized services right away). The team checks back with the medical officer to know how many of the referred children came to the PHC as per the referral; but they are not quite sure of these numbers as yet since this team started work in June.

#### **Analysis**

The reason for discrepancy between the two teams regarding the services/ facilities for referral is not clear and may perhaps be attributed to lack of training of staff on referral protocols. As per the RBSK strategy documents, children screened and found to have one of 30 conditions listed under the 4 Ds should be referred to tertiary healthcare facilities. The strategy does not recommend referral to the PHC. While the team that refers children with

problems to the PHC has a rationale for it i.e. the need to overcome issues of stigma associated with mental health issues, it does not entirely justify this referral as PHC currently does not have the skills and resources to provide the specialized services required by the child. So, if families that were referred came to the PHC, they are either likely to receive no assistance for their children's mental health issue (in case some PHCs are unclear about where to refer for such problems) or further referral to a tertiary care facility (and so direct referral to a tertiary care facility in the first place would have avoided unnecessary detours and delays for the children and families).

That said, the choice of places for referral and the problems of ensuring that referral instructions are followed by affected families certainly highlight community perceptions about child mental health, namely stigma and discrimination issues. It also raises questions about appropriate places for referral—that appropriateness is certainly defined by where the skills and services are available but that from the community's perspective appropriateness is also defined, and perhaps more strongly, by social acceptability and stigma/ discrimination criteria. Thus, there is also some merit in one of the teams' rationale for selecting PHCs as a first referral point, given that everyone knows and recognizes this space and that it has qualities of neutrality and non-discrimination i.e. there is usually no stigma attached to accessing care at the PHCs since people come to them for a range of health problems, most of which are non-stigmatizing.

Further, the team that follows RBSK protocols also recommended that after the initial consultation at a specialized service, PHCs should be the point of continued contact and follow up for children. As pointed out during the discussion, the PHC staff with their current capacity and skill in child mental health would be unable to support children and their families with follow-up inputs on child mental health problems, it is certainly a strategy that can be considered in the future, in various ways: i) through training/ skill building and increase in child mental health knowledge and skills of PHC staff; ii) collaborations between PHC staff and tertiary care services through periodic clinics run by tertiary care services within the PHC space (as recommended by one of the teams) to enable access to specialized and (possibly) stigmatizing problems in a neutral space.

The issue of affordability is cited as another major reason for referral and follow-ups not being implemented by families. According to the RBSK strategy guidelines, all children diagnosed with any of the 30 (listed) illnesses would 'receive follow-up referral support and treatment, including surgical interventions, at tertiary level free of cost under the RBSK program'. This provision requires to be made clear to the school health teams, who in turn, need to emphasize this to the schools and families of the children they screen. However, the tertiary care facilities where this treatment would be available free of charge must also be clear (namely public institutions) and the concerned facilities should be oriented to the RBSK programs and screening/ referral processes so that they are aware of the types of services to provide when they receive children identified through this program.

## d) Need for Training & Capacity Building

At the time of focus group discussions, no training had been conducted for the SHTs. Only a powerpoint presentation was available to all staff newly recruited, providing some basic guidelines about the RBSK and the 4 Ds. Later on, however, a 5 day residential training was conducted. The training program covered all 38 conditions listed the RBSK (in brief) and the training materials, also a powerpoint presentation were made available to the RBSK staff.

SHTs recommended that in addition to the training program, that the Dept. of Child Psychiatry at NIMHANS conduct training workshops for them to provide more in-depth inputs on how to understand and work with children. They also said that it would be useful if a screening tool could be developed and the teams could be taught to use it: "It would be good if you could do a session for us and show us how to screen...then we can identify children with problems—and even take some extra time to examine and give them inputs".

#### Analysis

Given that it is a recent initiative, the type of training that the state will undertake to provide to the newly constituted teams, requires to be examined. Should the focus of this training be largely the 4 Ds, in terms of signs and symptoms, it will be useful, as the teams suggest, to focus on skills on how to communicate with children and screen for child mental health problems in the short time available to them.

#### e) Other Recommendations from the SHTs

In addition to the various recommendations already mentioned in previous sub-sections, one of the school health teams suggested using the malnutrition community-based model for intervention to address community child mental health issues, namely disability. The screening and intervention approach used by the community-based malnutrition programs run by the PHC entails conducting of community camps: once a month, a camp is organized by the link workers in the community. Dates and venues are announced and parents are asked to bring their children on that day. At the camp, medicines, nutrition education and other requisite inputs are provided. Similarly, the team suggested, it might be possible to consult a camp for disabled children—so that parents can bring their disabled children and the link workers can provide inputs. However, they suggest that the link workers do a screening and identify disabled children (as is done in case of malnourished children), also stating that those missed out by the screening might still show up at the camp, thereby enabling further identification of children with disability. They claimed that the use of such a camp approach worked well for child malnutrition identification and treatment in the community.

#### **B.** Orientation Workshop

Following the focus group discussions, a one-day orientation workshop was conducted for school health team staff, namely doctors. There were 21 participants from 4 zones of Bangalore city. (See annex 3 for zonal representation).

## **Objectives and Content of Orientation Workshop**

The objectives of the orientation workshop were:

- To introduce the longer term community child mental health project and how it will support government and aided schools.
- o To provide an orientation on some key areas of working with school children:
  - School mental health issues including disability and emotional and Behaviour problems in school-age children
  - o Special issues such as corporal punishment, bullying and child sexual abuse
- To understand the school health team's needs/ areas for training & capacity building, and gaps and challenges in their work.

The orientation workshop included the following content:

- Preventive/ promotive and curative approaches in school mental health, including life skill interventions
- Disability basics: Identification of intellectual disabilities and specific learning disabilities
- Emotional and behaviour problems in school-age children: understanding the context of emotional and behavioural issues (anxiety, depression, conduct problems and ADHD), identifying signs and symptoms which are indicative of such problems, some basic methods of intervention.
- Special Issues: Corporal punishment; child sexual abuse
- o The role of school staff in school mental health
- Gaps and challenges faced/ recommendations for training and capacity building

The workshop focussed used case study and discussion methods to enable participants to obtain an understanding on identifying and diagnosing developmental disabilities, and emotional and behaviour problems in school children. Assessment and diagnosis was discussed with a view to enabling understanding about the context children come from and how these contexts (home/ family environment, (dis)abilities, school and peer group experiences etc) give rise to certain types of emotional and behaviour problems. Issues on how a single behaviour could occur due to different disorders i.e. how there could be differential diagnosis, were discussed.

## Common Emotional & Behaviour Problems identified by RBSK School Health Teams

Learning problems, Withdrawn/Isolated Behaviour, Hyperactivity, Disobedience, School Absenteeism/ Refusal, Depression, Difficult Family Issues,
Physical Injury (Due to Abuse), Poor Concentration, Poor Writing Skills, Anxiety, Speech Problems/ Stammering, Inhibited/ Quiet/ Anti-Social, Reserved/ Pre-Occupied, Slow Learner, Aggressiveness, Poor Peer Interactions, Low Self-Esteem (Due to Obesity/ Physical Disability), Inappropriate Sexual Behaviour, Impulsivity, Loss of Parents, Disinhibited Behaviours with Sexual Content, Convulsions

#### **Recommendations and Suggested Training Areas**

The school health team staff were enthusiastic about their work and appeared to be deeply committed to children's welfare. This was evident, not only in their interest and desire to learn more about child mental health issues but also in the frustration they expressed about being unable to respond to the problems they came across. Their role and functions only permit them to identify and diagnosis problems and provide referrals; they are not permitted medical interventions/ drug prescriptions. These restrictions appeared to have caused them to feel somewhat helpless and demoralized during the course of their work in the field.

Based on the discussions had with them, it is recommended that their roles are extended at least in the area of child mental health issues (including disability) in ways that enable them to provide first-level responses to children with emotional and behaviour problems, including parent and teacher guidance on home-based care and training for children with disability. The extension of their roles to include basic counselling would be highly beneficial to school children (and their families), for whom there are many barriers in accessing psychosocial care and support at mental healthcare facilities.

From the perspective of the RBSK scheme also, such a broadening of the school health team's role and function would result in more effectively meeting the program's objectives of screening and early intervention. While the key focus of the RBSK scheme (in terms of child mental health) may be developmental disabilities, the fact is that, like developmental disabilities, other childhood and adolescent emotional and behaviour issues are also rooted within a child development framework; and when children have emotional and behaviour problems, one or more of the key child development (physical/social/language/cognitive/emotional) are adversely impacted, thereby resulting in developmental lags and problems in others, because all the key domains of child development are so strongly inter-connected i.e. deficits in one domain can cause deficits in another. For instance, a child with cerebral palsy might have primarily a physical disability. However, due to her lack of loco-motor abilities and mobility, her social and peer interactions may be limited, thus impacting her social development, and similarly, in less aware families, she may be prevented from attending school, thereby depriving her of opportunities for social and cognitive development. In another example, a child with learning disability might develop school refusal problems, which is essentially an anxiety disorder, an instance of how a developmental disability can give rise to an emotional problem. Severe emotional problems, such as anxiety and depression, or behaviour problems such as conduct disorders, occur commonly in children living in difficult family or social circumstances, or those who are physically/ sexually abused, and result in decreased academic performance and other developmental problems. Many of the children who go to government schools (which the RBSK scheme serves) are drawn from vulnerable situations and experiences such as these.

Further, the field reality, shared by RBSK workers, is that they receive 'complaints' from teachers not only about children with developmental disabilities but also about children with emotional and behaviour problems, thus indicating that the RBSK teams need to be equipped to deal with a wider range of mental health problems. Thus, a sole focus on disability, without cognizance of associated emotional and behaviour problems, or without addressing the developmental delays and lags caused by emotional problems would not be an effective approach to promoting child development. The school health team under the RBSK scheme presents a critical opportunity to provide child and adolescent mental health care at a primary level, through efficient use of a school health outreach service.

#### 2. Education: Government and Aided Schools

The education sector directly caters to perhaps the largest number of children within a system. Given the prevalence of developmental and child mental health problems, problem identification and intervention at school-level is a very significant context for service delivery. Furthermore, school also offers a universal context to preventive-promotive mental health activity. The National Curriculum Framework, Sarvashiksha Abhiyan, the Right to Education Act and other progressive child initiatives all point to the tremendous scope that schools offer in fostering wholesome development of children and their identities. This scope is strongly recognized and recommended in the District Mental Health Program.

Thus, assessment and orientation workshops were undertaken with principals and teachers from government and aided schools. 32 school staff, including principals and teachers participated in these sessions on psychosocial and mental health issues in school children. They were drawn from 21 government and aided schools located within the selected PHC catchment areas in Bangalore South zone. (See annexe 4 for list of schools included).

#### **Objectives and Content of Orientation Workshop**

The objectives of the orientation workshop were:

- To introduce the longer term community child mental health project and how it will support government and aided schools.
- o To provide an orientation on some key areas of working with school children:
  - School mental health issues including disability and emotional and Behaviour problems in school-age children
  - o Special issues such as corporal punishment, bullying and child sexual abuse
- To understand school staff's needs/ areas for training & capacity building, and gaps and challenges in their work.

The orientation workshop included the following content:

- Preventive/ promotive and curative approaches in school mental health, including life skill interventions
- Disability basics: Identification of intellectual disabilities and specific learning disabilities
- Emotional and behaviour problems in school-age children: understanding the context of emotional and behavioural issues (anxiety, depression, conduct problems and ADHD), identifying signs and symptoms that are indicative of such problems, some basic methods of intervention.
- Special Issues: Corporal punishment; child sexual abuse
- o The role of school staff in school mental health
- Gaps and challenges faced/ recommendations for training and capacity building as well as for support to schools

# School Staff Knowledge and Skills: Observations and Discussions from the Orientation Workshop and Implications for Future Training & Capacity Building

It was explained to the school staff how training and support provided through the proposed community child mental health project will enable school principals/ teachers to:

- Increase school staff skills to deal with common problems faced within the classroom and children, by providing a greater repertoire of methods and responses i.e. a tool box they can draw from.

- Practice more effective classroom management strategies, especially in the light of the large numbers of children they have to deal with, including accommodating the needs of special needs children.
- Equip them with skills to identify and provide first level/ supportive response to common emotional problems (that are at mild and moderate levels) in ways that are effective but not time-consuming.
- Identify and refer serious child mental health problems, such as child sexual abuse or other disorders that require in-depth counselling and therapy.

However, at the end of the orientation workshop, the objectives of school mental health or child mental health in schools and their roles in it did not appear to have been understood by school staff (see adjoining box).

## **School Staff Responses to the Workshop:**

"We know everything you spoke about...but we cannot focus on one child and forget the others".

"We cannot spend all our time managing these difficult children".

"We know how to respond...I like children and I tell them I like them and believe in them."

"We have no time for anything extra".

"Your job is to counsel them all day...not our's."

"Government school children come from such environments that nothing is effective—this is how they are."

"We give them two slaps to stop hitting each other; else, the child who has been hit complains at home and his parents come to school and fight with us and hit the child who hit their child."

"We are not allowed to give corporal punishment. What are we to do?"

"Once when in fourth standard, I ran away from school. I was caught and beaten by my teacher. I never did it again. I believe I am what I am today because I was punished like that.

### **Knowledge of Developmental Disability**

While some teachers appeared to be aware of developmental disabilities such as ADHD, even especially concerned about them, they had no knowledge as to how to manage these children i.e. in terms of special attention or tasks in keeping with their abilities, classroom management strategies to address the needs of these children more effectively. The concept of resource rooms, where a child with special needs can be engaged with through 'pull-out time' and given one-to-one attention is not known to the government school systems.

In case of other disability-related issues such as specific learning disabilities (SLD), there appeared to be only a vague understanding that it was a reading-writing-mathematic disability and not a global disability. The responses to SLD children ranged from: "We encourage them in other areas" to "We encourage them to read and write...and when they demonstrate other talents or do well in other areas we tell them that they should do as well in reading and writing as they do in other areas." The latter response is worrying as it indicates that teachers have not understood the issue of SLD i.e. that it is not a problem of children's effort/motivation and therefore that it would be unfair to pressure the child to do well in reading and writing, especially in a classroom and with a curriculum that is not geared to their special needs; nor were they clearly aware of the workings of the National Open School so as to be able to guide SLD children to avail of such enablement. While they acknowledge that a number of children have problems with reading and writing, they do not appear to assess, even in a broad sense, whether the disability is due to SLD or intellectual disability. Consequently, a blanket response to all children with academic performance problems appears to be to 'encourage them', implying that all academic problems are due to children's motivational problems—irrespective of whether the cause of the problems is motivationrelated disability-related or whether it is a consequence of emotional issues (such as depression and anxiety).

#### Responses to Children with Emotional and Behaviour Problems

The confidence that they 'know everything' and 'do everything' is not corroborated by their responses to the case studies set out in the workshop. For instance, schools staff clearly acknowledged the challenge of dealing with children with conduct disorder, which was also one of the most frequently mentioned behavioural issue (the other one being ADHD). Some stated that they had attempted to use strategies such as assigning leadership roles to conduct disorder children in the hope that giving such responsibilities would prompt them to change their negative behaviours. In some instances, they claim that this strategy worked; however, a majority of the school staff were cynical about these children and did not really believe that behaviour change was possible: "Oh we just do something and manage...just give them two smacks or threaten and shout at them...nothing ever makes a difference...we just try to manage somehow like this, to go from day to day". They also found it difficult to attribute conduct symptoms to harsh/ punitive or neglectful family circumstances and to develop an understanding of the context and emergence of the behaviour of such children. Even following explanations on the basis of conduct problems, they continued to maintain the simplistic view that "Government school children come from such environments that nothing is effective—this is how they are." Thus, school staff have a very limited repertoire of responses for dealing with children's behaviour problems.

Further, they did not identify emotional problems by themselves, in relation to academic performance issues or as a basis for other behavioural/ conduct problems. For instance, a major part of their work is focussed on school drop-outs. The reasons they identify for school drop-out are: i) financial problems at home due to which children are forced into labour and due to which parents also prioritize children's economic activities over school education; ii) economic issues in the family also force both parents to work long hours, starting very early each day, so that older siblings have to be caregivers to younger ones and stay home to complete domestic chores; iii) lack of motivation on the part of some children who 'just don't want to go to school because they would rather be at home on their own, with no supervision and watching television and playing instead of studying."

While the first two reasons are widespread causes of school drop-out, particularly in socio-economically vulnerable urban areas, the third reason i.e. motivation requires more careful consideration. Lack of motivation, which translates into school refusal could be due to: i) trauma/ life changes (leading to anxiety); ii) problems at school with teachers/ peers (including bullying, violence, abuse that may make a child very fearful of school); iii) problems with academics (such as specific learning disabilities or mild intellectual disability that leads to performance anxiety and frustration in class); iv) problems on the way to school (bullying/ abuse that may lead a child to avoid going to school). From our observation, school staff do not appear to have a more nuanced understanding of 'motivation problem' in as much as this may be somewhat true at times; even in such situations, however, where there appears to be no other cause, there are reasons pertaining to parental neglect or disinterest, which also need to be examined and addressed. Reasons for school refusal or drop-out issues therefore require to be examined in greater depth and with considerable sensitivity, in order to effectively respond to such issues.

## Responses to Special Concerns (Bullying and Child Sexual Abuse)

Schools do not appear to be equipped with strategies to address problems of bullying. Again, while some teachers mentioned working with the bully by assigning him leadership roles and tasks of responsibility, there was little or no response to the victim. The victim, they say, is mainly asked about what happened and who bullied him and told not to bother about the incident. Most situations are dealt with by calling both the bully and victim and telling the bully 'don't do that again' and asking the two to 'be friends'. This is the most common response to peer conflicts in general and those related to bullying. The teachers also acknowledge that this method of conflict resolution may not always be effective because it does not necessarily stop the bullying, and in fact it may make it worse for the victim as the bully is angry that the victim 'complained' to the teacher. It is also an approach that does not provide a response to the victim i.e. one that should be based on reassurance and justice, because the school has no anti-bullying policies and treats the issue lightly, and at par with other minor peer conflicts. There does not appear to be a recognition among school staff that bullying, unlike other forms of peer conflict, is also a form of peer abuse and that this may have serious consequences later on-because what is termed as ragging in college (and has led to severe physical and psychological consequences, including death) has been found to begin in school at the level of bullying.

While school staff acknowledge the gravity of an issue such as child sexual abuse, also believing that it is their responsibility to address it, whether or not it occurs within the school premises, especially when the child has told them, they do not have a clear idea on how to go about first level responses to child sexual abuse. The knowledge that they response/ actions have to be three-part i.e. systemic (including informing the school authorities, the education supervisor/ BEO, the CWC and the police), what they will tell parents and how they can guide them about where to seek help, and what they can tell the child in terms of providing reassurance and ensuring confidentiality. They are aware of the POCSO Act but still claim that in such instances, parents refuse to allow them to report to the police and other systems; it thus appears that teachers also lack the confidence to take a position on children's issues, as not in the case of CSA but in other day-to-day school conflicts too, they are fearful of parental responses to their actions.

#### **Attitudes to Corporal Punishment**

Following the National Commission for Protection of Child Rights guidelines against corporal punishment for children in schools, school staff stated that there has been a considerable decrease in the use of these methods for disciplining, and many teachers said that they 'never' use these methods. However, others said that some corporal punishment methods were still used, albeit of a less serious nature. This indicates that there was a likelihood that the school staff responses to discussions about use of corporal punishment was influenced by social desirability factors i.e. there might have been some hesitation in acknowledging that 'a few slaps' were given now and then' or that children 'had to be threatened' into good behaviour.

There are other indicators that suggest that teachers continue to use corporal punishment: i) they have little knowledge of alternative methods of disciplining whether through use of positive engagement methods or through adoption of permissible negative reinforcement methods; ii) complete helplessness therefore on 'how else' to discipline children; iii) considerable difficulty managing large numbers of children and specific individuals with problem behaviours, in which instances some of them openly acknowledged that 'nothing else works' and no method is effective—although they also admitted that hitting and threatening only yielded short-term results and temporary good behaviour.

Further, even where school staff know that corporal punishment for children is against education/ child rights guidelines and they are duty-bound to follow these guidelines, the helplessness and frustration they voiced in therefore being unable to 'control' children, was evident. Thus, it appears that there is a reluctance in following corporal punishment guidelines because they do not actually see or understand the rationale for it; their own upbringings and cultural and belief systems legitimize its use.

#### **Challenges Faced**

A number of challenges faced while fulfilling their teaching duties, were outlined by the school staff:

- Classroom management of large numbers of children.
- Managing children with special needs within the classroom.
- Disciplinary issues (minor issues such as late comers to major problems such as conduct disorders)
- Adolescent issues such as truancy, emerging sexuality
- Creating awareness among/responding to parents
- Dealing with school drop-outs
- Heavy report-writing and administrative work (thereby limiting teaching time).
- Educational policies and laws such as the RTE which place complex day-to-day and administrative problems on the school system

#### **Perception of Role in School Mental Health**

At the end of the workshop, despite various discussions on school mental health and children's psychosocial issues, the school staff did not appear to see a role for themselves in the mental health of school children. There were absolutely no responses when asked about their role; instead they listed the challenges they face as government school staff. From their recommendations, it appears that they do not wish to undertake any additional roles, not even if it is embedded within their teaching roles and is not a time-consuming extra burden

i.e. there is no envisioning of a role for themselves in the lives of children beyond teaching them the 3 Rs and discharging other community and administrative duties as required by the Dept. of Education.

They are open to external agencies to coming into provide child development and mental health services as long as they are not involved in the service provision process. They suggested that those external agencies, such as NIMHANS/ the project 'come to school and see our problems and deal with problem children' or 'provide school programs for children' and 'create parent awareness'. In all these activities, they merely said that they would assign children and provide the space—there was no mention of their involvement or skill building in these areas. While they listed areas of need and types of children who posed challenges to their work, there seemed to be little interest or desire to want to learn how to handle them.

In fact, they spoke of training fatigue, saying that they had undergone training in several issues such as subject teaching, learning disability and community interventions (pertaining to prevention of child marriage, school drop-outs etc). However, they have had little exposure to child mental health issues. Further, the impact of some of these training programs is hardly evident—for instance, their knowledge and response to children with learning disabilities is inadequate.

While the school staff acknowledge that they have a bigger and more powerful role to play in children's lives than literacy and numeracy, the challenges that they face in carrying out their designated responsibilities are simply too overwhelming for them to consider the larger role of education. Thus, they do view themselves as agents of social change but are voice their frustrations and helplessness in actually executing this role.

#### Problems posed by Right to Education Act: An Education Coordinator's Anguish

"We spent the whole day on this problem yesterday...even the BEO was there. In one of the schools under us, a child with disability was sent to the school. Because of RTE, the school had given him admission. But the teacher could not manage this 9 year old boy because he also had a lot of behaviour problems and issues with his peers—along with the disability. The parents of his peers demanded that the school issue a TC to this child. But the child's parents insisted that the school retain the child...and the school is bound by the RTE, and so cannot force the child out of school. The parents of the other children threatened the school—saying that if you do not get this child out, we will remove our children and get them admitted elsewhere. If this happens and the school has insufficient numbers of children, then it will be forced to close down. What are we supposed to do? Whose side should we take? We have no solutions to such problems."

Such occurrences, according to education coordinators, within the Dept. of Education, are common, with conflicts

Such occurrences, according to education coordinators, within the Dept. of Education, are common, with conflicts ensuing between school management, parents of the disabled child and parents of other children, each party fighting for its rights and interests to be maintained, each with its own legitimate concerns. This is not to say that the RTE is not a valid or legitimate act and one that would be beneficial to all children, in particular, those who are vulnerable due to disability or discriminatory actions. But the objective of application of the RTE to children with disability is mainstreaming such children into the regular education system. However, mainstreaming is not a random one-off process, nor is it limited to merely seating a disabled child in the classroom of a regular school. There needs to be a process to mainstreaming and this includes:

- Assessing the nature of the child's disability including associated emotional and behaviour problems.
- Decisions about the placement of the child based on detailed assessment including the nature and severity of the disability so that the child is placed in the most appropriate educational setting/ developmental centre.
- If it is determined that the child's disability is mild (intellectually), in which case the child can be mainstreamed into normal school, the child and family need to be prepared for the challenges of integration.
- The school/ teacher needs to be prepared with special skills and strategies to be able to handle a child with different needs.

Such protocols and processes need to be in place for the RTE to be able to function effectively and address the needs for mainstreaming and integration within the educational system. Else, neither the school system nor the concerned special child is benefitted from arbitrary processes of integrating children with special needs into regular systems; in the name of mainstreaming, they only become mere acts of tokenism.

#### Recommendations for Integrating Child Mental Health Issues into the School System

In the light of the reluctance of school staff to be involved in child mental health issues, the community child and adolescent project might have to adopt a different approach from the one originally envisaged with the education department, through government schools. The following are the recommendations for the ways forward:

- Contrary to the original plan, the project will not provide an in-depth child mental health skills training workshop for school teachers as this may not be well-received or have any impact (reasons stated in the above sub-sections).
- Instead, the on-the-job training component of the capacity building initiative will be introduced first. In this, project staff will visit each of the selected schools on a regular basis and assist school teachers with
  - i) Classroom management strategies and creation of resource spaces (to the extent feasible).
  - ii) Identification and referral of children with developmental disabilities and acute emotional/ behavioural problems;
  - iii) Identification and management/ counselling of children with mild-to moderate levels of emotional/ behavioural problems (i.e. those not requiring referral)

Such assistance and counselling will be provided to schools/ children contingent upon the condition that the school provides a teacher(s) to be part of the work/ process of engagement with the child. This will thus demonstrate to the teacher how individual work with children in need can be done and allow him/her to be part of regular follow-up.

- Project staff, in collaboration with teachers, will implement (and therefore demonstrate) life skill program packages with the children.
- Over time, based on the involvement of school staff and the motivation and interest of individual teachers, the in-depth skills training workshop will be implemented.

## 3. Child Welfare: Anganwadis and Child Care Institutions

The Dept. of Women and Child Development (DWCD) administers one of the largest welfare schemes in the world viz. Integrated Child Development Scheme (ICDS). The ICDS primarily serves children between ages 0 and 6 years to provide nutrition, health and developmental activities that include non-formal education. Since a large number of children attend the anganwadis from underserved and vulnerable populations, these centres constitute critical locations for early identification of disabilities and offer opportunities for preventive-promotional child development activities.

There are an ever increasing number of governmental and non-governmental organizations working with vulnerable children from difficult circumstances. Many of these institutions offer residential care. Since many of these children come from backgrounds of neglect, deprivation, abuse and trauma, in addition to addressing their developmental needs, they require specialized interventions focussing on their mental and emotional well-being.

This section presents assessment findings for the two groups of child welfare agencies administered by DWCD, namely anganwadis and child care institutions (CCIs). The latter are divided into five broad categories as per the target population/ types of children they serve.

### 3.1. Anganwadis

45 Anganwadi workers (1 worker per Anganwadi) were provided with a one-day orientation session on psychosocial and mental health issues in pre-school children; in the process, they also participated in the assessment focussing on their needs, challenges and skills to work with pre-school children. The workers were drawn from anganwadis located within slum areas of selected 13 PHC catchments in Bangalore South zone. (See annexe 5 for list of slums/ areas covered).

## **Objectives and Content of Orientation Workshop**

The objectives of the orientation workshop were:

- To introduce the longer term community child mental health project and how it will support anganwadi teachers' work.
- To provide an orientation on some key areas of working with pre-school children
  - child development
  - identification of disability
  - o emotional and behaviour problems
- To understand anganwadi teachers' needs/ areas for training & capacity building, including previous training undergone, and gaps and challenges in their work.

The orientation workshop included the following content:

- Key areas of child development (physical, social, cognitive, speech & language, emotional development): skills and abilities that pre-school children need to develop and types of activities that may be used to develop them.
- Disability basics: a tool for basic screening and identification of developmental disabilities in pre-schoolers and application of child development activities for disability-focussed interventions.
- Emotional and behaviour problems in pre-schoolers: understanding the context of emotional and behavioural issues, identifying signs and symptoms that are indicative of such problems, some basic methods of intervention.

- Special Issues: Corporal punishment; child sexual abuse
- Anganwadi worker experiences: previous training, gaps and challenges, recommendations for training and capacity building

# Anganwadi Workers' Knowledge and Skills: Observations and Discussions from the Orientation Workshop and Implications for Future Training & Capacity Building

#### a) Child Development Theory and Practice

The anganwadi workers, due to their basic training, have a good knowledge of child development and are also resourceful in terms of the activities they conduct in order to maintain and promote child development, from a psychosocial perspective. That said, their knowledge of the five areas of child development were not uniformly superior. They knew more about physical development and social development than they did about the other three areas i.e. speech and language, emotional and cognitive development. In fact, during their feedback, they stated that they learnt most about pre-schoolers' emotional issues during the orientation workshop as they knew very little about it previously.

While they have a basic understanding of the domains of child development, they lack conceptual clarity i.e. they are not easily able to connect the activity to the domain and the skills/abilities it involves (example story telling as an activity that develops children's speech and language or cognitive abilities); and therefore, they are unable to conceptualize specific activities with a clear objective of helping the child achieve or develop a specific skill/ ability i.e. activities are all done with a general objective of enabling developmental abilities in children.

#### b) Identification of and Response to Developmental Disability

Anganwadi workers are able to identify some signs and symptoms of disability, such as children being 'silent' or 'isolated' and 'playing on their own', hyperactivity, or those who have physical disabilities and speech problems. However, there is no systematic method or tool used to screen the child and establish that the child has a developmental disability. They are therefore also not knowledgeable on what type of interventions to develop for children with mild to moderate developmental disabilities. While they acknowledge that such children require special attention and more time, they were not sure what types of approaches and activities to use with them. A related issue was how to tell the difference between a child who appears to have a disability because of what is really an emotional problem versus a child whose problem is due to a developmental disability; for instance, a young child's behaviour of silence/ isolation and refusal to interact with her peers could be due to some degree of intellectual disability which impairs social skills or it could be due to emotional issues arising from family or home contexts.

#### c) Understanding of and Response to Children's Emotional and Behaviour Problems

As mentioned above, anganwadi workers' abilities to understand and identify emotional problems in young children were inadequate. Their observation of emotional and behaviour problems included: isolated/ silent children, excessive crying when separated from parent/ caregiver to go to the anganwadi, children who refuse to participate in activities/ play with others, children who cannot sit in one place/ are hyperactive and hyperactive, hitting and biting or snatching other children's things, children who do not like to share their things. There was also limited understanding or analysis of why children behave in these ways or

express such emotions; while the workers are aware of the types of homes these children come from i.e. families with marital discord and alcoholism, or where parents are busy at work and have no time for the child, where young children are mostly cared for by an elder sibling (also a child), the workers are unable to link the children's emotional and behaviour problems to the contexts to which they are exposed to. Consequently, when asked how they handle children in such situations, they appeared to have an extremely limited repertoire of skills and responses. Their responses range from value-based judgement and advice ('don't do that, it is bad') to disciplining (threatening or use of physical punishment—mainly smacking the child) in case of aggressive or difficult children; and they tend to provide material response ('don't worry. What do you want? I will get you whatever toy you want...') in case of children who are anxious or crying.

#### d) Disciplining and Corporal Punishment Issues

While all the anganwadi workers are aware that corporal punishment is unacceptable and 'wrong', not many were aware that it is 'against the law'. In fact, it was new information for them that the National Commission for Protection of Child Rights has guidelines against corporal punishment. They needed sensitization that there are different levels to behaviour problems of children ranging from minor to severe. The response to the different level also needs to be different but even where there are severe behaviour problems (such as physically aggressive children), they cannot be responded to with corporal punishment. While the anganwadi workers accepted that sometimes they may resort to mild smacking, it had to be pointed out that even the threat of punishment is considered inappropriate, especially in case of very young children. Thus, there seems to be a lack of orientation to behavioural management of difficult children, which includes a range of approaches such as understanding the child's background, the context of the child's needs, and issues of provocation. Their gaps in knowledge and skill also pertain to discussing behaviours with children in a non-judgemental fashion and use of behavioural strategies like creating opportunities for pro-social behaviour, providing positive feedback, and anticipating potentially aggressive situations.

#### e) Response to Child Safety and Protection Issues

The group was sensitized to about the recent spate of child sexual abuse cases. Many anganwadi workers had their own accounts of children whom they had encountered, who had been abused. While not many had encountered this in the course of their work with preschool children, it was observed that there was no systematic personal safety training done for anganwadi children. Furthermore, when asked what their response would be if a five-year old was to report being inappropriately touched, for example, by a neighbour, the anganwadi workers lack knowledge about a systematic protocol of response and reporting. Thus, deficit areas identified here include: i) how to respond to the child; ii) how to guide parents; iii) where to report (knowledge about CWC); iv) a system of internal reporting including onward information to the supervisor and CDPO; v) where to seek expert assistance for the child; vi) provisions under Prevention of Child Sexual Offences (POCSO) Act.

## f) Previous Training Received

All anganwadi workers undergo a basic training, upon joining, for a period of 1.5 months. This initial training program focuses on health education about hygiene and maternal and child nutrition issues, immunization/ polio, and child development. The training covers issues such as child marriage and child mortality, which also feed into the health education

sessions that the workers hold for parents/ caregivers within their communities. The child development component does not cover emotional and behaviour problems in children, nor the skills for response; it does not include corporal punishment issues nor the laws against it, such as the NCPCR guidelines about corporal punishment. No orientation on child sexual abuse, including the POCSO Act is provided in the training program.

A large component of the training includes data collection and record keeping on anganwadi attendance, pregnant and lactating mothers, immunization, growth-monitoring, child malnutrition and food distribution. For children identified with disability, their role is limited to referral, so they are only told (in the training) where to refer. The documentation does not create a space for children with emotional and behavioural issues, nor disabilities.

## g) Curriculum, Standards and Materials Available

Anganwadi workers said that they have a set curriculum and time-table to follow. Each day's schedule includes: health and hygiene session, action songs, pre-writing skill activities, story-time, rest and lunch, games/ physical activities. Thus, the methods are the same but the subjects/ themes may vary—each week a theme, such as flowers, fruits or seasons is selected and all activities and methods are geared to delivering knowledge on these themes. There is no systematic monitoring of the quality of these educational activities; the anganwadi supervisor visits each anganwadi once or twice a month and during her visit, observes activities and may ask the children some questions. The Child Development Program Officer (CDPO) also visits from time to time but not regularly.

Anganwadi workers receive a standard kit which includes pictures and charts, plastic alphabets and numbers, plastic fruits and vegetables and a few toys. They also receive a contingency grant of Rs.84 per month, of which they have to spend half on soap and cleaning agents; the remaining may be spent on consumable materials they require for teaching. Overall, they report a general shortage in materials available to them to conduct developmental or educational activities.

#### h) Challenges Faced

In addition to limited materials, anganwadi workers report two other challenges: the first is that they have very limited space to conduct activities; they also face issues such as being asked to provide toilet training to the children when there are no toilets in the anganwadis. The second is the problem of time; they are so over-burdened with record-keeping and documentation and other tasks such as attending to the requests of pregnant mothers that they are left with very little time to interact with the children and actually do activities with them. As a result, one of their concerns were how, after undergoing any in-depth training program, would they be able to implement all that they learnt and whether the Community Child Mental Health project would be able to develop a curriculum that recognized the limitations of their work environments and how the project would be able to support and advocate for them in ways that would enable them to have a stronger focus on child development and education work.

#### **Anganwadi Workers' Recommendations**

Anganwadi workers participating in the orientation program stated that they had benefitted greatly from the inputs on emotional and behaviour problems in young children and they were keen to receive more in-depth, skill-based training in this domain, including on disciplining and child sexual abuse. They also strongly recommended that: i) the training be

provided to all anganwadi workers from other zones (as they were aware that their colleagues would benefit from the knowledge and skills as they had even during the brief orientation provided); ii) the emotional and behaviour training contents be added to the existing 1.5 month training program received by all anganwadi workers at the time of joining.

# Recommendations for Upcoming Training and Support for Anganwadi Workers Design a training curriculum that includes the following:

- Application of child development concepts (versus mere theory)
- Conceptualization of methods and activities within child development frameworks
- Systematic screening and identification of developmental disabilities (including basic screening tools)
- o Interventions for developmental disabilities and associated behaviour problems
- Orientation on common family and community contexts that anganwadi children come from (such as alcoholism, marital discord and domestic violence, single-parent families...)—how such family systems can be dysfunctional and how this dysfunctionality impacts child development i.e. a more nuanced understanding of how such contexts place children at risk of emotional and behaviour problems.
- o Basic communication and response techniques with pre-school children,
- First level responses and management of common emotional and behavioural issues in pre-schoolers.
- Corporal punishment/ disciplining, alternative methods to manage children with behaviour problems
- o Teaching children about personal safety (prevention of child sexual abuse)
- First level/ emergency responses to child sexual abuse including identification of CSA, reporting guidelines and POCSO Act

Support and advocacy for anganwadi workers needs to include the following, through discussions with the DWCD:

- Duplication of work between anganwadi workers and ASHA/ Link workers.
- Scope of their responsibilities that goes beyond 0 to 6 to prenatal care on the one hand and adolescent girls on the other and how this results in further over-burdening them.
- Extensive and cumbersome systems of reporting that compromise the time allocated to direct work with children.
- Space and material limitations that hinder their abilities to do quality work with the children.

#### 3.2. Child Care Institutions

As mentioned in the earlier section on community mapping, the CCIs were broadly divided into five categories: those working with i) street and working children; ii) orphan and abandoned children; iii) children with disability; iv) HIV affected and infected children; v) children with gender and sexuality vulnerabilities. (Refer to annex 6 (a) for CCIs contacted and annex 6 (b) for initial categorizations).

The objectives of the workshops were:

- 1. To obtain detailed organizational profiles of each agency, including information on:
  - Needs and problems of the targeted children
  - Types of services offered
  - o staff numbers (particularly those directly engaging with the children)
  - Staff knowledge on specific contextual issues pertaining to the children they serve.
  - Staff Training and capacity building needs
- 2. To refine the first-level mapping exercise by adding information on the variety of services provided by agencies i.e. categorizing agencies in more than one group based on the range of children they serve or services provided.
- 3. To enable agency staff to critically examine their work with children, the knowledge and skills they have, and the gaps thereof, in providing children with psychosocial care and support.

Objectives 1 and 2 were achieved by requesting the CCIs attending the workshops to fill out a detailed organizational profile. This data has been summarized in Annex 6 (c). Objective 3 was achieved through discussions in the workshop—both small group work and plenary discussions were used to enable the staff to think through various issues that pertained to their work and analyse the gaps in services and skills thereof. The basic content of each workshop was as follows:

- Listing and categorizing of needs/ risks/ vulnerabilities of target groups.
- Establishing initial contact with children
- How/ what emergency/ immediate are assessed and addressed
- Relationship building with children
- Types of emotional and behaviour problems commonly observed
- Methods/ techniques/ interventions used to address emotional and behaviour problems
- How medium to long term needs are addressed
- Special concerns pertaining to specific categories of children (as applicable)
- Gaps, challenges and need for training and capacity building in each of the above areas.

Refer to Annex 6(d) for workshop content and guidelines.

The content of the discussions with each category of CCIs are detailed out in subsections 3.2.1 to 3.2.5 (below). They are detailed out first in terms of the actual findings i.e. what CCI staff said about what they do/ the methods they use to engage with children and provide services, and then in terms of analysis i.e. what the findings mean for child and adolescent psychosocial health and what the gaps and

challenges are, and therefore, what the needs for staff training and capacity building are).

## 3.2.1. CCI Category 1: Street and Working Children

# a) Organizational Target: Needs, Specificity and Rationale for Selection of Target Group

The first issue for discussion was why agencies were specifically reaching out to a particular target population and what specific needs of this target group made them work with this group versus others. Most agencies describe their agency's services, including the target groups they reach but without a clear rationale for why they specifically work with this group. There were only a couple of exceptions to this: One agency spoke about how severely underserved children in conflict with the law were, a difficult group to work with and one that is also highly stigmatized and discriminated against; the other explained that their work with disability was based on their observation and studies in the area of Mandur, where the sociocultural practices made for high rates of consanguinous marriages, leading to a high number of disabled children, to whom inhuman treatments were meted out due to poverty, and lack of awareness of families. Another agency dedicated to working with underprivileged children in residential shelters, also spoke of chronically/severely physically disabled children as being their focus because families either did not want to or were unable to care for these children.

Other agencies described their services, largely to include basic needs provision (including care and protection as nearly all agencies run shelters and residential homes), education and vocational training, raid and rescue, and counselling. While staff were able to describe the social issues pertaining to street and working children, such as runaways, they were able to describe the needs and risks of these children more in terms of substance abuse and criminality. Other mental health risks, including emotional needs, did not appear to be part of the larger thinking of agency managerial staff. For instance, some agencies, particularly those working with only girl children, did not mention the vulnerabilities and mental health needs of girl children, not only in case of sexual abuse but also in terms of developing a sense of self and sexuality. An important aspect of well-being and affirmative identity in the context of sexuality is to heal from abuse in a manner that the entitlement to a fulfilled sexuality in a legitimate relationship is experienced by the girl in question. This entails an embracing of sexuality as a positive dimension of human experience and the confidence to engage in it without negative connotations. This type of depth and nuanced work does not appear to be part of the routine of the agency. The approach is more information, safety and reassurance-based.

Similarly, for children with problem behaviours such as anger and aggression, the approach appears pre-dominantly behavioural, with the intervention being value-based and therefore mildly disapproving. What was found lacking was an exploration of the (legitimate) origins of the behaviour, and interventions based on approaches that are more reflective and respectful. Furthermore, it is known that many children with these types of problems have a serious background of trauma, loss and grief. Not addressing this is a problematic lacuna.

#### b) Services: Quality Monitoring and Impact Assessment

Most agencies were unable to describe parameters or indicators they used for quality monitoring of their services or impact of their work on individual children. Some agencies said that they defined impact as the child being able to have 'a dignified life in society'. When

asked to further define this, one agency said that it meant: 'child has got a skill and gained employment'. Another agency working with girl children said that it meant getting the girls to realize the 'importance of having a profession (versus only getting married), good sexual health and how to behave in a professional setting.' Other agencies did not state any ways of measuring or attempting to understand the quality and impact of their work. Some even preferred not to engage in this discussion saying that 'you have to come and see our work, come and visit us...only then can you see and feel what we do.'

Only one agency mentioned having developed a database that contains information records about every child, from the time of rescue/ initial contact to when the child leaves the institution, including an individual care plan. The nature of information contained in this database pertains to the child's social and family problems, rescue situation, health and education; details about counselling needs are not documented here.

Some inputs were provided about the need for agencies to consider systematic ways to monitor service quality and develop parameters and check-lists to track the progress and impact of their work with children, based on both individual and group needs and problems.

#### c) Internal Resources: Infrastructure and Staffing

Most agencies said that they had sufficient in-door space and infrastructure to be able to provide children with shelter and other basic needs; some said that they had a lack of outdoor/ playground space for the children. The other major internal resource issue, staffing, prompted discussion on several concerns:

- Agency staff are not oriented to mental health issues.
- Many staff come from difficult circumstances and have personal/ mental health issues themselves.
- Staff turn-over is very high due to low salaries (BSW salaries are Rs. 1,500; MSW salaries are Rs.4,000).
- Non-MSW/ non-trained staff have a tendency to stay for long periods of time, while MSWs/ trained staff tend to leave for better remunerated government or corporate jobs.
- A lot of staff motivation strategies are required, including one-on-one time with them, to ensure that they are performing their tasks or that they are a good fit for their jobs.
- Staff are often busy fulfilling donor requirements vis-à-vis documentation etc and this leaves them with little time for actual work with children.
- Staff strengths are mainly to do with rescue work and meeting immediate needs of children, namely basic/ physical needs. But work that entails getting into children's psychosocial problems is difficult for them to do i.e. they are able to complete systemic procedures but not really do in-depth individual work.
- Current levels of staff skills pertain to in-take and assessment but do not extend to problem identification especially in the areas of child mental health and psychosocial care.

Some agencies were not able to articulate staff capacities at all. For instance, one agency head said: 'there is a need for the staff to be really involved with the children...and that is it.' Another agency said that staff motivation had to do with them feeling 'is it for a cause?' and that passion was instilled in staff by giving them a position in the agency, upward mobility and performance appraisal and feedback.

Some response and inputs were provided in these instances to agencies to help them think along the lines that their work involves 3 main elements: i) intention; ii) operational process; iii) methodology. The discussions aimed at getting agency staff to think about the difference between these three elements and to consider what level their work with children was at.

# d) External Resources: Other Stakeholders, Collaborations with Government, Non-Government and Community Institutions

Nearly all agencies largely mentioned funding agencies and donor support when asked about their collaborations with other agencies. However, some of them discussed the need to be able to collaborate particularly with government institutions, such as schools and primary healthcare centers, saying that such collaborations would enable their children to use government facilities and services more effectively.

When asked about agency media or advocacy strategies, only a couple of agencies mentioned the use of the NGO Forum for Street and Working Children, which has not been very active in recent years. Some NGOs mentioned that they had managed to do some grassroots level advocacy—an example of this was how they advocated for small shops around railway stations and bus-stands in certain areas to stop selling glue fluid in bottles to reduce easy access/ abuse of this substance.

#### e) Initial Contact Issues

Street children being highly mobile and reactive to the environment are a very challenging group to work with. Most often, they demand tremendous effort and energy of the field staff to effect any meaningful change. While the work involved has become reasonably systematic, there are aspects that are still uncharted; truly reflective of the life of the child on the street. Not always can positive feedback or results be clearly identified or defined as models to be adopted elsewhere.

The dynamics of the initial contact involves deliberately establishing a relationship with a street child. This relationship is unlike any other social or therapeutic relationship. Regularity of contact cannot always be ensured. The contact, when made, is often very brief. This briefness places an additional strain on field staff to engage in rapport building, collect relevant information and to refer the child to appropriate agencies. To be alert to psychological issues over and above this constitutes a serious challenge. Help-seeking on part of the street child are highly fluctuant. Levels of formality also vary as articulated in the efforts that field staff make to ensure cultural consonants, peer comfort and incentives, in communication (refer to figures below).

The field staff need to recognize that the street child may or may not desire this interaction and thus the child's response could be positive or negative. In the discussions there appeared to be a tendency to gloss over these difficulties and present a picture that mere field presence, cultural consonants and commitment was enough to meaningfully engage the street child.

However, once there is a meaningful relationship established and unique problems of children emerge, a new set of challenges are thrown up (refer to figures below). For example, children with substance abuse are a challenge to work with because expectations for reflexivity, agency, responsibility and notions of risk are seriously compromised as part of street socialization. In fact, reflection is not good for short-term survival and non-reflection is

method of coping. Add to this the lack of access to information and services and low self-efficacy beliefs regarding personal change, and the challenges compound. Because of the combination of accessibility, normalization, unsupervised freedom and peer influence, many of the common risk behaviours (substance abuse or harmful sexual behaviour) become challenges to work with. Field staff do not have training on working with children with special needs or with methodologies that relate to trauma. Basic security/ supportive work may be done but depth approaches that focus on developmental interventions on the one hand and healing interventions on the other are lacking as problems such as disability or trauma emerge in understanding the child in the initial contact process.

#### f) Emotional and Behaviour Problems

The staff mentioned a number of emotional and behaviour problems that street and working children, living in institutions, have:

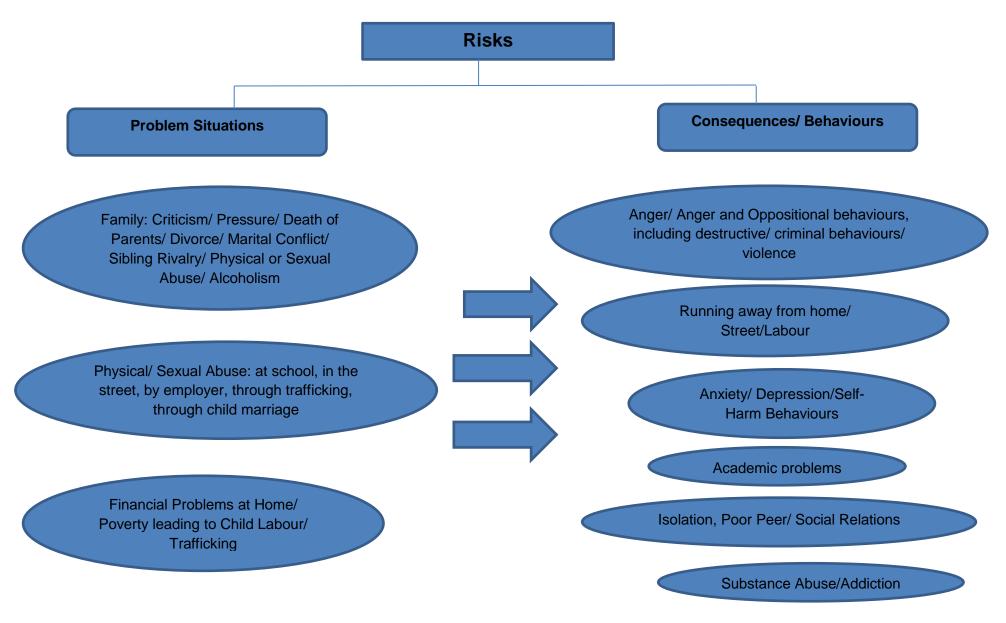
- Suicide and self-harm behaviours
- Substance abuse/ addiction
- Need for security and bonding
- Need for decision-making skills and prioritizing
- Attention-seeking behaviours
- Aggression, ranging from oppositional/ defiant behaviours to anger, property destruction and disturbing other children
- Low interest/ lack of motivation in academics, including poor performance and poor concentration
- Complaining frequently about stomach aches (and other aches and pains, especially when taken to the doctor)
- o Poor peer relations
- Truancy/ runaway behaviours
- Adolescent problems (apart from substance abuse) include 'love', bullying and abuse of younger children

#### Analysis

The staff are unable to explain or analyse the basis of these problems. While there is a broad sense of awareness that these children come from difficult circumstances and will therefore have problems, there is no understanding that while most children may be 'street children', each of them has a different history and life experience i.e. that the contexts they came from, before arriving at the (NGO) institution were different, and that consequently, while they may even display similar emotions and behaviours, the reasons for them cannot be lumped into 'street children having lived in difficult circumstances'. Even as staff know, due to their extensive daily interactions with children, some of the children's histories and stories, they are not aware of how they are linked to or manifest as emotional and behaviour problems.

Further, there is the perception that certain issues such as the 'need for security and bonding' that children have, are problems, rather than viewing them as natural emotional needs that all children would have, and ones that children from difficult circumstances might have a heightened sense of (due to previous deprivation) is also normal.

## Street and Working Children: Risks and Medium/ Long Term Issues



#### **Places of Initial Contact with the Child**

Places/ Spaces of Initial
Contact

Raid/ Rescue Spaces (Child labour/ Trafficking)

Remand Homes/ Shelters/ Residential Homes

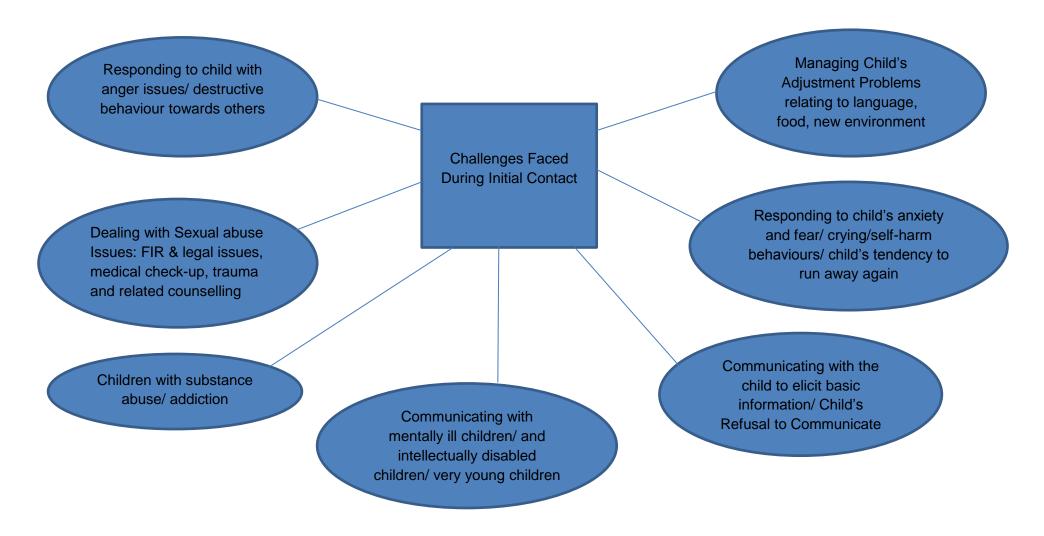
## **What Initial Contact Processes Entail**

What Initial Contact Entails/ Methods Used Rapport Building and Personalization of Interaction: Introduction of Self and Child, Active Demonstration of Concern & Empathy, Use of non-verbal methods/ Body Language to Appear Friendly, Joint Games

Information Gathering and Documentation: Obtaining basic information on child's family history/ social status /interests /problems; identification documentation (photograph and contact numbers) as per agency protocol

Other Methods: Provision of incentives (sweets & toys) for child to engage/ communicate; Use of Cultural Consonants (such as using language familiar to the child); Facilitating peer interactions to increase child's comfort level

## **Challenges Faced During Initial Contact**



#### g) Response to Emotional and Behaviour Problems

Most staff were not aware of methods that could be used to deal with the above-described emotional and behaviour problems children have. There was some mention of behaviour therapy techniques but the staff was unable to explain its use. One agency spoke about how they dealt with love and sexuality issues through the use of drama. They stage (street) plays for children about the pros and cons of love marriages and arranged marriages, showing how the latter succeed far more than the former, with a view to convincing children that 'falling in love' is not appropriate and is not considered 'good behaviour'. Another agency staff corroborated this by stating that they counsel girls about the 'negative consequences' of love relationships.

One reason the staff stated for not being aware of methods of response was that they are not involved in 'counselling' children—there are special counsellors designated to do so. The counsellor, who sees the child, is aware of the child's problems and, for confidentiality reasons, does not reveal them to other staff in the institution. However, the staff say that due to their daily and extended interaction with the children, they usually know a lot about the children and their lives because children (even without promoting) tend to share their stories and concerns with the care-taking staff.

### Analysis

While many street and working children attempt to impart life skills (and state that they do life skills group activities with children) on issues such as sexuality and relationships, they appear to follow didactic positions, adopted as a result of their personal opinions and viewpoints. This contradicts the essence of life skill promotion work—which entails that all individuals participate equally in the production of knowledge, and that this is a continuous dialogue; and that learners are the subject, not the object, of the process. What this means is that life skill development is not about articulating one's own positions and convincing the adolescent to adopt the same beliefs; it is about adopting an open stance (despite one's own experiences and personal opinions) and creating a space for debate and discussion, so that adolescents can examine and analyse an issue or situation from multiple view points and come to their own conclusions on what might be the best course of actions. In this, the use of creative methods such as stories and narratives, theatre and other art forms, help create the life situations and contexts (such as marriage, sexuality, conflict etc) that form the basis of the discussion.

It is apparent that the staff have not received much training about use of methods to address children's emotional and behaviour problems. While it is heartening to note that many agencies have specialized staff to play the role of counsellors, as stated by the staff, counsellors are not there all the time—they have fixed days and times when they see children. Second, it is the caretaker staff who spend maximum time with the children and interact with them on a continuous basis, so it is important for them to have some basic, first-level response skills to assist children, especially as children frequently articulate their concerns to the staff.

Provision of support and appropriate responses to children cannot be restricted to a counselling context, for a pre-determined period of time, in the same way as therapeutic work with children in specialized settings (such as clinics or hospitals) is not done in the absence of parent counselling. The purpose of parent counselling is to ensure some environmental modifications and continued support to the child outside pre-set therapy times with a counsellor; this is similar to the supportive functions that child care (care-taker) staff in an institution play in the daily/

overall care of the child. While the counsellor's role is critical in a children's institution, in bringing specialized skills to provide in-depth therapeutic responses for specific problems and issues, it is essential that the children are supported at other times too—not in specialized ways but by other care-taking staff using basic communication and supportive techniques to ensure: i) children's psychosocial well-being and developmental trajectories are maintained; ii) to contain existing emotional and behaviour problems and thus prevent them from becoming worse. So, in fact, the counsellors' roles should be extended to working with the institution staff, providing some inputs on dealing with/ supporting children with problems--and this can be done in ways that do not endanger the child's confidentiality by providing some basic/ necessary information about the child's situation and the type of assistance required, without revealing highly sensitive details about the child's life.

# h) Conclusions and Recommendations for Street and Working Children CCIs: Implications for Training

Overall, it appears that agencies engaged in the care of street and working children have a strong focus on protection, limited to raid and rescue, and followed by provision of basic needs (food/ shelter/ healthcare) and education. Other elements of protection that include personal safety and life skills, future orientation, risk-benefit analysis, establishment of supportive networks are conspicuously lacking.

Undeniably, these agencies are working in difficult environments, and with challenging target groups; the importance of their work and contribution can therefore in no way be undermined. This work has a strong field context and addresses the immediate needs of the target group/children. Many agencies also run shelter-based programs. However, both individual street work and shelter-based programs appear to lack a strong systemic or conceptual strategy. Even for a given child, there is a difficulty in articulating a long term care plan, which has a strong, systematic basis of assessment and an understanding of the child's individual characteristics or contextual specificities. This is also evident in the ways in which the field staff described their work and methods.

Further, Many agencies have a mission statement that articulates the intent of the work. These intentions, well-founded as they are, refer to issues such as protection and development in a generic way. The programs and methodologies therein through which these are actually executed on the field are not that clearly articulated. Thus, it is difficult to guage, for a given child, exactly how intervention processes play themselves out. Even agencies that have considerable experience in the field, for many years, were unable to engage in levels of thinking that use organizational and service delivery approaches i.e. a systematic understanding of the needs and risks of target groups, the agency's response to these needs, the methods used for response; the effectiveness of these responses, including parameters to measure effectiveness and impact; the internal and external resources required to meet needs/ implement responses and the gaps and challenges thereof.

#### Areas for Staff Training:

- First contact assessment with a mental health focus.
- Problem identification and analysis/ detailing
- More structured counselling processes, including how to build rapport/ trust, systematic use of creative and other methods to address emotional and behavioural issues
- Skills to work with more complex problems relating to sexuality, risk behaviours, abuse and trauma

- Documentation of intervention processes
- Monitoring of change over medium and long term
- Working with children towards clearer future plans (including life skills)

<u>Note:</u> The first round of needs assessment and sensitization workshops included CCIs engaged with street and working children. As reflected in the above documentation, some efforts were made to engage agency heads in discussions about organizational issues, such as agency mandates, monitoring and evaluation of programs/ services, impact and quality evaluations, internal and external resources available etc. However, since a systems perspective, more specifically, organizational analysis abilities amongst these agency staff was limited, the attempt was abandoned as not being useful. In subsequent needs assessment workshop, therefore, discussions were focussed purely on field work issues—and staff were better placed to address these.

#### 3.2.2. CCI Category 2: Orphan and Abandoned Children

## a) Context of Contact

Agencies receive children from the Child Welfare Committee (CWC), police, hospitals, and other agencies such as Childline. Children are also drawn from single-parent families or families where both parents may have died; sometimes children are also relinquished by their families/ relatives who may be unable to take care of them due to financial or other reasons. All such processes go through the CWC.

The children may be as young as neonates in adoption agencies who then shelter them for the first 6 years; if they are not adopted they are transferred to other fit institutions for older children. Other agencies (non-adoption agencies) that provide care and protection accept children from age 4 onwards. While they do not accept infants, they prefer to take in younger children as they feel that they bond better, especially in agencies such as SOS which have family model of care, with house mothers who have a group of children under them. In such agencies, 4 to 10 year olds and older girls (until age 18) stay in one home; boys are transferred to a separate home after age 14.

#### b) Immediate Issues and Responses

Issues in the immediate aftermath of the arrival of children at the institution are as follows:

- Fights among children
- Cleanliness and first aid
- Documentation (getting the child's history/ details)
- Emotional ups and downs in children
- Adjustment problems, especially in the context of loss i.e. if children have lost both parents, they find it harder to settle down and accept their new surroundings.
- Feelings of instability due to frequent changes i.e. this is case of children who have been transferred from one home/ institution to another.

When asked how institution staff contend with these initial issues, and help children to make the transition to a new place and situation, many said that they 'treat new children with extra affection and give them more attention than others'. One agency said that 'since some of our house mothers/ staff come from difficult backgrounds, they understand the need to make a child comfortable—so we know'. One agency said that they have rituals for welcoming the child i.e. upon arrival, a child receives gifts and chocolates and there is an 'aarti' ceremony to welcome the child into the home.

#### Analysis

CCI staff appear to have a limited understanding of how to respond to children's immediate needs and issues, other than the material. There seems to be an expectation that given (a probably improved) material needs situation, children will automatically adjust to their new environments. What was not evident in the discussion was:

- Whether staff have an understanding of the child's past
- Whether the child knew or understood the reasons for coming to the home (and if the staff were cognizant of such issues and gaps and how they affected the child's perception of the new environment).
- How a child's anxieties about a new place are addressed.
- If the child was transferred from another institution/ home, how the decisions about (Inter and intra transfer) transfer were made and if the child was part of these decisions.

The staff did not appear to perceive the importance of preparing a child to deal with a new place and situation by way of explaining what to expect, new routines etc. They do not reflect an understanding that such systematic ways of enabling a child's adjustment are important to the child's acceptance of the environment, and that medium to longer term consequences of not following such processes are anxiety, feelings of lack of belonging and ownership. This is because predictability, especially in the initial stages of settling down, is critical for a child moving to a new space and situation.

Furthermore, they do not seem to perceive the significance of loss issues and the role these play in helping a child settle in i.e. while they recognize that a child who has lost both her parents has a harder time adjusting than others, their response does not entail at least at a minimum acknowledging this loss and providing a first-level response to loss.

#### c) Relationship Building Processes

CCI staff responses on how they establish and build relationships with the children they care for in their institutions mostly consisted of how they 'look after children with love'. With regard to younger children, they said that they sat children on their laps and used touch and cuddles to build a relationship with the child, and that they respond 'with concern' if the child is upset or falls down/ hurts himself.

Agencies that serve older children said that upon arrival, they place children with their peers, with whom they are left to interact; they then 'speak' with the child later. An introduction of the child to his/ her peers and general questions to the child i.e. conversations with the child help the child understand that 'they will be together'. They may also find out the child's interests, such as music or art, and ensure that the child has opportunities to learn/ participate in such activities. One agency stated that they use a strategy by which every week, some of the children go with child care staff to the market and this is a time when relationships are built.

Some agencies mentioned that 'all children are asked to draw...observation of child tells us what the child's issues may be'. Many agencies said that 'observation of the child, without the child's knowledge' helps the staff understand whether the child is well-adjusted or not and what support the child requires. They also said that 'regular follow-up of the child', on whether the child is healthy or has behavioural problems or responds appropriately helps them understand the child. One agency also mentioned that there is an individual file maintained for each child and this contains all information about the child. Before or at the time of the child's admission, the agency gets details of the child's background so that they know all about the child.

#### Analysis

Bowlby proposed that children who grew up in orphanages were unable to love because they had not had the opportunity to form a solid attachment to a mother-figure early in life<sup>11</sup>. This attachment is an emotional bond that occurs between two people and is essential to healthy relationship building. For orphan and abandoned children, the development of a coherent and affirmative self-identity is critical. Part of this has to do with reconciliation with their past history and the circumstances of their being orphaned/ abandoned. Sometimes this history is clear albeit painful; other times, the past story is not very well-known. In either case, to develop a sense of self-worth, including the significant experience of attachment, it is imperative for current attachments to form a bridge between this problematic past and the anticipation of a positive

<sup>&</sup>lt;sup>11</sup> Bowlby, J (1969).Attachment and Loss (Volume 1). Basic Books. USA

future. Furthermore, it is likely that the current relationship of staff with children will also be time-bound. To thus develop a balanced relationship that combines strong elements of attachment, affiliation and a stabilizing passage to more independent adulthood is an essential task for the staff of an orphanage/ institution.

This process cannot be merely through observation or information gathering. Even if there is a file system with information about the child, or systems by which the child is observed, there is a distinction between knowing about the child (through observation and direct eliciting of information) and building a relationship with the child. The latter is about having a connection with the child. Most of the strategies used by the CCI staff are means of obtaining information about the child (no, doubt an important task), not means of establishing a relationship with a child.

There was little mention of activity-based relationship building—such as use of play, or relationship-based rituals of child care workers—such as something special or unique used to connect with each child (a special toy or a special name). While activities such as art were mentioned, the question is how such a cross-sectional activity is converted into a relationship process; for instance, one month later, do the staff take the drawing book and discuss the drawing that the child had done and what the child remembers of the discussions had at the time? For, it is such processes that build and maintain continuity in staff-child relationships.

Further, there is a distinction between the needs of the child and knowing the child as a person; the latter entails the child's unique personality, including his/ her temperament, likes and dislikes, strengths and weaknesses. Enduring patterns of behaviour, including inner experiences such as conflicts and aspirations as well as self-perception and a future vision for the self constitute true personhood. It is in the experience and understanding of this true personhood that the depth of a relationship lies.

## c) Identification and Understanding of Emotional and Behavioural Issues

CCI staff listed some of the common emotional and behavioural issues that orphan/ abandoned children in their institutions have:

- Aggressive behaviours: child does not listen/ disobedient, stubborn, back chat and rudeness
- Passive anger—not interacting with anyone/ sitting alone
- Fighting with each other (some children do this more frequently)
- Being moody, sitting on his/ her own,
- Excessively shy,
- Bed wetting
- Attention seeking behaviours: some that occur on a daily basis, such as children wanting to be fed by a particular volunteer/ staff or wanting to be fed first (before other children); crying to get attention or toys/ food; 'demanding attention' and 'testing how important they are' by sitting in a corner and refusing to talk (until they are persuaded extensively); throwing temper tantrums (particularly younger children).
- Value for money not perceived.
- Bullying other children
- Telling lies or stealing
- Don't accept their mistakes/ don't like being corrected
- Influencing younger children (in negative ways)

The reasons staff attribute to such emotional and behaviour problems are:

- 'They occur when something one child likes is given to some other child'.

- 'When they do not get adequate attention and love'.
- 'Bad experiences of some other place/ institution they stayed at or of home'.
- 'Memories of parents'
- 'Staff not being kind or cooperative with them.'
- 'When another child is paid more attention or praised.'

#### Analysis

The above-mentioned emotional and behaviour issues are reflective of some of the types of problems that children from orphanages typically exhibit:

#### Poor Self-Regulation

A combination of rigid routine with on-going changes in the environment, over which children have no control, frequent turn-over of caregivers and transfers between institution create unpredictability in living arrangements, which in turn lead to a great sense of instability and lack of control. Children's daily routines are usually fixed schedules with almost no personal choices and no private possession of toys or other things. This combination of rigidity and lack of control results in children living in a 'reactive' mode surviving one day at a time. Poor behavioural self-regulation in such children may be observed in various ways:

- i) Difficulty in sustaining goal directed behaviour including generating problem-solving strategies and methods of achieving goals, implementing activities towards this end, following complex instructions, monitoring and keeping track of performance.
- ii) Emotional volatility or the inability to modulate emotional responses, as these children are easily aroused emotionally, whether they are happy or sad, and the speed and intensity with which they move towards the extreme of these emotions is relatively high.
- iii) Reluctance and unwillingness to perform tasks that are repetitive, uninteresting or require effort or have not been chosen by the child, including difficulty in making shifts, resisting certain behaviours or avoiding acting on impulse.
- iv) Difficulty with delaying gratification and accepting 'no' for an answer in which behaviour they resemble those of children much younger then their age.

#### Mixed Maturity

Poor self-regulation results in children who are actually older behaving like younger children; while in terms of self-care and certain chores they perform, they might be advanced for their age, in stress/ frustration tolerance, they behave in ways the usually children seberal years younger than them behave.

#### Learned Helplessness

Children in orphanages have been conditioned to receive more attention from caregivers when they appear helpless—because the independent children in an institutional environment are, the less attention they receive.

Hyper-Vigilance and 'Pro-Active' Aggressiveness

Children who have been neglected and traumatized in their early yearstend to display highe levels of aggressive behaviour. Hyper-arousal, a heightened alertness and vigilance combined with an inability to correctly interpret the emotional side of a situation, is typical of orphanage children and it results in problematic social interactions with peers and adults.

### Feeling of Entitlement

Given the nature of life in an orphanage, when food and other items are delivered seemingly equally to everyone in the group, there are feelings of entitlement created in children. While non-institutionalized children may also have a sense of entitlement, children in orphanages have a heightened sense of this entitlement: they are conditioned to believe that if one member of a group has something other members of the same group are supposed to get the same, too,

whether they need it or not. They may not understand the appropriateness of their demand. This sense of entitlement, when it manifests in an extreme form, could lead to behaviours such as lying and stealing, in order to obtain things.

#### Extreme attention seeking

Because adult attention is a relatively scarce commodity in an orphanage, children fiercely compete for attention, sometimes through use of negative behaviours, as they feel that even to be punished is better than to be ignored. Thus, children constantly seek adult attention, approval, and encouragement. Often, no matter what they do, the motivation is to evoke a reaction from the grown-up, not to solve a problem or achieve some goal<sup>12</sup>.

In order to better understand and address children's emotional and behavioural concerns, it is important for staff to have conceptual clarity on the psychology of abandonment/ orphaned status. Many of the behaviours observed in these children are a psychological fall-out of the insecurity, anger and sense of entitlement that abandonment causes. Thus, observed behaviours, however difficult to handle they may be, need to be seen as the consequence of the above-described problem areas rather than as isolated behaviour problems without a basis.

Further, staff knowledge on child development, particularly of staff from those CCIs that serve young children (aged 0 to 6 years) appears to be low as they made no mention of children having developmental delays or disabilities. It is well-established that many children from orphanages, due to lack of consistent caregivers ('mothering'), and limited social and emotional experiences, have developmental delays and deficiencies. These delays and deficiencies persist even as children grow older. For instance, children who have spent several of their early years in orphanages show cognitive deficits including rigidity in thinking, inability to generalize solutions to specific problems, poor logical and sequential reasoning, excessive concreteness of thought, poor concentration, attention regulation, and inhibitory control, and restlessness and fidgeting. Emotional problems include internalizing and externalizing behavior problems, social and peer relations (including problems regulating emotion, anger, aggressiveness), indiscriminate friendliness, and attachment problems<sup>13</sup>.

Lastly, none of the emotional and behaviour problems that orphaned and abandoned children exhibit are viewed in the context of their loss experiences. We have referred earlier to the dynamics of abandonment. Children are likely to feel distress at the idea of being unwanted, or resentment because of the limitations of circumstances that compelled their families to abandon them, or anger at fate having dealt them a bad hand or feeling intensely entitled to 'compensation' and therefore even grabbing/ demanding attention and affection. What is missed in this legitimate formulation is the theme of loss. While CCI staff may have a poignant sense of the circumstances of children's abandonment, their notions about how loss is experienced by children is not well-developed.

<sup>13</sup> St. Petersburg—USA Orphanage Research Team (2009). The Effects of Early Social-Emotional and Relationship Experience on the Development of Young Orphanage Children. Monogr Soc Res Child Dev. 2008; 73(3): vii–295.

<sup>&</sup>lt;sup>12</sup> Grindis, B (2012). Post-Orphanage Behavior in Internationally Adopted Children as cited in Centre for Cognitive-Developmental Assessment and Remediation. Available at <a href="http://www.bgcenter.com/BGPublications/OrphanageBehavior.htm">http://www.bgcenter.com/BGPublications/OrphanageBehavior.htm</a> (accessed on 9th October 2014)

#### d) Response to Emotional and Behavioural Issues

When asked how staff respond to the emotional and behaviour issues they observed, most of them said 'with love and affection' and 'by providing children with comfort...and by coaxing or persuading them (to do things)'. Other responses to this effect included 'develop a good rapport with the child and provide adequate affection', 'understanding their pain' and 'providing acceptance'. Sometimes they also said that they ignore the behaviours.

Some agencies mentioned 'speaking with the child' or 'sending the child for counselling'. One agency said that they conducted life skills classes to 'build resilience in children.' One staff said encouraging children to do well in various activities of his interest was a way to handle emotional and behaviour problems while another mentioned use of 'jokes, laughter and pictures' to get children to control anger.

#### Analysis

Since developmental delays and disabilities are not identified in children (due to low awareness and knowledge on the key domains of child development i.e. physical, emotional, cognitive, social and language development), the use of early stimulation materials and methods, for infants and young children, were not mentioned. Indeed, when asked about young children's development, the staff appeared to focus primarily on physical growth, that too from a nutrition perspective (including medical issues). Physical growth in terms of, loco-motor skills and abilities are not an area of focus and there was little evidence of caregivers in orphanages that serve young children having such skills or training.

Since there is a limited understanding of the basis of the emotional and behavioural problems children in orphanages have, there are few systematic methods used to address them in older children. Staff do not appear to have an in-depth understanding of some of the critical issues that result in emotional problems in orphan/ abandoned children—namely lack of attachment figures, a lack of a sense of belonging and ownership. From these basic gaps, arise deep-seated feelings of deprivation, from which other emotional problems (such as emotional lability and attention seeking) and behaviour problems (such as anger and aggressiveness or disregard for orphanage property/ money) arise. Methodological practices to address a problem, such as use of play/ stories etc to address a child's emotional and behaviour problems does not appear to exist, nor do the practice of behaviour management techniques.

Loss and grief are by and large domains that have few practitioners. In a sector such as orphan and abandoned children, loss is likely to be a fairly universal theme and dynamic. It stands to reason that staff of CCIs that deal with these children be oriented to understanding loss and grief and providing the appropriate healing interventions. As stated earlier, this is not the case. While the circumstances of abandonment may be known/ evocatively described, the manner in which this constitutes a loss experience for the child is not that well-articulated. What is more concerning is the absence of specific approaches/ methods to address loss and grief even when it may be known/ partially understood. There is a simplistic assumption that provision of material needs and pleasant conversation and affectionate caring will compensate for the loss. The fact that loss and grief especially if they have occurred under complex circumstances need deeper forms of intervention is not adequately recognized. Thus, orphan and abandoned children grow up with a deep unfulfilled sense of completeness.

#### e) Recommendations for Training and Capacity Building

- Response to immediate needs and issues from a mental health perspective, including children's participation in decisions about their placement.
- More effective relationship building strategies with children, including activity-based relationship building.
- Skills for early stimulation for children under 6 years of age, in adoption agencies as well as orphanages that admit very young children.
- Activities and tasks based on child developmental principles so that staff can enable children to maintain age-appropriate developmental trajectories (i.e. not limited to emotional/ behaviour problem response only)
- Identification and understanding of emotional and behaviour problems
- Systematic use of creative and other methods to address emotional and behaviour problems in children
- Special skills to respond to loss and grief issues in children

#### 3.2.3. CCI Category 3: Children with Disability

## a) Assessment and Identification of Disability

All agencies ask for government disability certificates at the time of admitting the child to their institution, except in case of some agencies that have religious affiliations, where children are accepted through the child welfare committee (CWC) and police, or even abandoned at their gates. In the latter cases they go through the necessary procedures with the CWC. Most agencies have in-house staff to conduct assessments of the child and determine the type of severity of the disability. They also have protocols/ assessment forms and tools to enable this process. While some agencies have developed their own tool or 'admission form', others have adopted standardized tools such as the Madras Developmental Program for Mentally Challenged tool, which assesses twenty domains of child development. One agency mentioned liaising with paediatricians and physiotherapists from St. Johns and Baptist hospitals to conduct assessments for the children in their institution; the staff's assessment is more through observation of and interaction with the child (versus a systematic information in-take approach). According to the agencies, the emotional and behavioural aspects associated with the disability or occurring as co-morbidity, are also documented in the assessment, whether through use of standardized tools (in cases where these are used) or in assessment forms developed by the agency, where they claim there is space for documenting 'all problems the child has'.

#### Analysis

Two issues emerge from the discussions on assessment: First, while there is no problem with agencies relying on external specialized/ medical teams to conduct developmental and disability assessments, it is essential for the in-house team, especially special educators and those working directly with children to be able to also participate and conduct systematic assessments of the child. This is because the in-depth understanding that emerges from directly assessing a child will feed more strongly into the care and interventions that are then designed and provided by these staff. Mere reliance on reports of visiting experts may not be sufficient and will not complete the understanding required for staff engaging with the child on a day-to-day basis.

Second, where agencies do not use existing standardized tools for assessment, there is the danger of i) the child's associated emotional and behavioural issues being obfuscated under 'all other problems the child may have' i.e. by not asking specific questions that will help elicit information on emotional and behavioural issues, they may be able to obtain only what the parent perceives as being problematic and miss other issues that are important; ii) the child's developmental abilities and needs not being clearly articulated if these specific domains (of physical development, speech and language, social and cognitive skills) are not mentioned during the assessment process i.e. asking about the child's abilities to perform activities for daily living is only one major part of disability assessment; other key developmental areas are also critical to evaluate, not only because they relate to activities for daily living but they are essential to the child's development of personhood (which cannot be reduced to a set of daily functions being performed).

#### b) Availability of Resources and In-House Facilities for Training and Stimulation

Most agencies who participated in the workshop run residential homes for disabled children (this may not be true for others in the city who run a range of services from day care facilities to vocational training units); one agency said they had a day care facility only. These facilities have a modest space with some play material and provision for occupation therapy. Neither the equipment nor the nature of activity seems to be systematically organized in terms of a daily

routine or follow a professional protocol of individual(ized) intervention plan (IIP). All the agencies have quasi-formal collaboration for resource provision in the areas of general health, speech therapy and physiotherapy.

## c) Disability-Focussed Interventions

When asked to describe what types of disability-focussed interventions were used by child care workers i.e. what they did on a day-to-day basis to enable these children to grow and develop, the agency staff provided activity descriptions that ranged from beading, colouring, singing, story-telling, reading, writing, indoor and outdoor games to the use of a sensory room (in one agency) and activities for daily living (how children were taught to brush their teeth or make their beds).

Most of these activities are done in groups; the sensory room is small and children take their turn to be in it in small groups. When asked about individual approaches, all staff said that they did practice individualized approaches. One of them provided an example: "every child must sit before the mirror each day and say his name and say what clothes he is wearing."

#### **Analysis**

Most agency staff were able to provide a description of the types of activities conducted, especially those who were special educators. However, what was missing in their discussions were specific objectives of the activities and how they did not appear to relate them to specific areas of child development or disabilities in children. Implementation of activity-based learning programs is certainly a strength that all the agencies seem to demonstrate in their discussion; but only planning and implementing activities with clear frameworks and objectives, including routine and frequency of engagement in the activity will effectively achieve the desired results in skill development. For instance, based on the needs of the child if specific objectives (such as locomotor development and speech and language development) are set, with a list of activities to correspond to these objectives (such as outdoor play, hand exercises for locomotor development and story-telling, use of picture card descriptions and telephone games for speech and language development), there would be a clear basis for the child to engage in certain types of activities, consequently enabling him/ her to achieve specific skills.

Further, the current interventions did not seem to be linked to a future plan i.e. there was no future projection in the care plan. Issues such personal safety, in anticipation of adolescence and early adulthood and the risks therein were relatively neglected in comparison to day-to-day issues or standard developmental interventions. In other words, life skills for adaptive survival, beyond basic needs/ independence and self-help, are nor addressed in interventions for disabled children.

Also, despite acknowledging that they have individual education plans, other than maintenance of separate files for each child, there did not appear to be much evidence of this. This is not to say that the staff or special educators are now aware of the nature and specificity of each child's problem or disability; but it does appear that this knowledge does not translate into design of interventions that are in keeping with an individual child's needs. When this issue was discussed, the staff acknowledged this to be true—that most activities were done for groups and the numbers of children and limitations of time made it difficult for them to provide individualized interventions.

## d) Identification and Management of Associated Emotional and Behavioural Problems

The emotional and behaviour problems associated with children with disability were listed as follows:

- Disruptive behaviours/ disturbing other children/ throwing play things
- Speech problems
- Memory and concentration problems
- Anger and aggression (such as biting other children)
- Inability to sit in one place
- Not socializing with other children/ being silent and isolated/ crying
- Some kids want to do very specific things—for example, in book cover-making, some children do not want to touch the glue at all and will only do folding.

The agencies said that they maintain individual files with records of each child's emotional and behavioural issues and that these files are periodically updated with the progress the child makes.

When asked about how the (above-mentioned) emotional and behavioural issues are managed by the special educators or other agency staff, the responses were as follows:

- "Give the child what he wants and leave him outside for a while...but show a lot of affection and talk lovingly...otherwise, if ignored, the child cries".
- "Give individual attention....give the child whatever he wants—or distract him with rhymes and talk."
- "Allow the child to choose what he wants to do or prefers doing...if he wants to only do folding and not put glue, then he can do only that."

Although not articulated by the agency staff on their own, when specifically asked, they spoke about sexual behaviours of disabled adolescents being a concern. They mentioned behaviours such as genital handling and self-stimulation as being problem behaviours, particularly among adolescent boys. Their responses are to forbid the adolescent from engaging in such sexual behaviour by speaking sternly to the adolescent, threatening to beat the child or deprive him of his snack/ food, put the child in bed for the whole day (children dislike this very much and apparently view this as a punishment). They sought to understand how such children, given their intellectual disability gauged (the teacher's) disapproval when they perform these acts, also saying that they found this a difficult issue to handle.

#### **Analysis**

While some key symptoms of ADHD and autism, which frequently occur as co-morbidities in children with disability, were mentioned, and the staff appear to identify other frequently occurring problems such as anger and aggression, they spoke in terms of individual children rather than being able to make generalizations about common issues. This may stem from a lack of understanding of the types of children with disability are likely to have; again, this goes back to the issue of not always having systematic assessments that elicit specific information on emotional and behaviour problems.

Management of emotional and behaviour problems appears to be a real knowledge and skill gap in these child care workers. While they speak of individualized approaches, there is no evidence of any methods or strategies being used to manage behaviour. For instance, no common models of understanding or analysing behaviour management, such as the ABC model for understanding

and managing behaviour problems<sup>14</sup> are used. Knowledge of such analyses is essential to be able to develop and use systematic interventions that result in behaviour modification. Currently, the response is at an individual level, largely entailing giving into the child's demands and providing comfort and reassurance—these are not effective methods, particularly in case of behaviour problems.

\*Inputs were provided on how children with disability behave in certain ways or practice repetitive behaviours because they are soothing and therefore, how it is important to provide them with alternative sensory experiences in order to modify behaviour and that other behaviour modification methods also exist. A brief discussion was also had about the sexual rights of disabled people and child care workers views on what they would consider as appropriate sexual behaviour for disabled adolescents or whether they would consider it appropriate at all for these adolescents to engage in any type of sexual behaviour, including self-stimulation.

#### e) Management of Safety Risks

While child care workers recognize the increased safety risks to children with disability, especially risks of sexual abuse, they are not aware of what methods they could use to teach disabled children about personal safety. One person mentioned trying to tell children not to talk to strangers while another from a religious institution said that the sisters of the Home 'take children out to show them people and tell them how to be outside versus inside (in the home)". They were very keen to learn personal safety strategies that they could teach disabled children, and made a special request for this issue to be included in the upcoming training workshops.

One agency that offers Diploma programs in autism, mental retardation and specific learning disabilities strongly suggested that the personal safety module be incorporated into the study programs so that teachers are systematically trained to teach personal safety concepts to disabled children. The development of a module by the team of this project for inclusion in the curriculum of the above-mentioned diplomas is very much part of the kind of enablement that future initiatives of this project wish to offer.

\*Inputs were provided on the ways in which children can be taught about personal safety and how the window approach can used to gradually introduce safety and privacy concepts that can lead on to basic discussions on body mapping and abuse-related issues.

#### f) Parent and Caregiver Support Programs

The agencies participating in the workshop had mixed views and experiences about parental involvement and support programs. Some of the key concerns about working with parents, especially those from rural areas are that : i) they are often unable to understand the nature and implications of intellectual disability; ii) consequently, they have extremely high expectations of a school or institution working with the child, believing that their child will at some point be able to 'go and get a college degree'; iii) they are also find it difficult to see or acknowledge the progress their child has made (having been in an institution/ with special training) in certain areas such as self-help skills both because of lack of understanding of the nature of disability and placing more importance on social parameters like educational qualification over issues of critical care-taking

<sup>&</sup>lt;sup>14</sup> The ABC model for behaviour management includes: A- Antecedents (What occurs before the behaviour/ what may have caused it?); B- Behaviour (What happens during the behaviour/ what does the behaviour look like?); C-Consequences (What happens immediately after the behaviour occurs?)

significance such as independent living skills. Of course, it was also stated that not all parents were unappreciative of the skills their disabled children had developed.

The other salient point made by the agencies was about how home-based training programs and inputs are often not followed by parents. When children from rural areas return home (from institutions) for holidays, staff report that they 'deteriorate' or 'forget all they learnt' because their home environments are not conducive to practicing what they were trained in. For instance, in their village homes, due to the absence of toilets and the general practice of open defecation, children are unable to continue to adapt what they have learnt in the institution to their natural habitat. Furthermore, agency staff said that teaching families behaviour modification techniques that entailed reward and incentives was not practicable: many low income families, who also have several children, have insufficient time to spend with the disabled child and inadequate resources to be able to provide special rewards or incentives (however small, such as in the form of everyday foods) to their disabled child.

Another issue highlighted was that, realistically speaking, no matter how good or detailed the home-based inputs provided by an agency might be, parents have difficulties in implementing them. As one agency staff, also the parent of a disabled child, said: 'parents do not have the authority that teachers have', meaning that they are unable to get children to do things at home that teachers manage to get them to do at school. This inability was attributed to the nature of parent-child relationships, which tends, particularly for disabled children, to be 'softer', 'more indulgent' and more 'permissive'. While this may vary from one family to another, the idea of permissiveness was extended to excessive protection. One of the agency staff spoke about how his agency had arranged for disabled individuals to serve food at parents' meetings and how parents took objection, saying that their children were being burdened with work. Thus, staff pointed out that there needs to be a balance between facilitating self-reliance and ensuring protection—a balance that parents often find hard to maintain.

#### **Analysis**

It appears that agencies are well-orientated to working with parent groups and have a fairly strong and insightful understanding of the limitations of home-based programs and how effective they are. The emerging issue therefore is enabling agencies to implement parent and caregiver support programs that take into consideration the challenges they outline, to adopt a more nuanced and practicable approach to home-based care. This entails adaptation of current home-based care strategies, that draw from largely western norms and are delivered as an ideal package, to more realistic, indigenously developed or suitably modified interventions, with a focus on the resources and abilities of low income households.

#### g) Mainstreaming and Advocacy

Only two agencies mentioned sending children to normal school. One agency said two of their children went to a government school wherein they sat in class with other children of their age but were given separate activities (mainly art and scribbling) to do. The objective, as per the agency, is just to get these children to develop social and communication skills though peer group interaction. The other agency said that they had managed to provide some initial training to some of their children with moderate intellectual disability and then place them in regular schools near their homes. However, due to their IQ limitations, these children have managed to study up to the 7<sup>th</sup> grade, following which they have dropped out. This is because, as per the State education policy, there is automatic promotion of children until the 7<sup>th</sup> grade, after which they can

only be promoted based on their academic achievement. One agency also mentioned sending a child to the Association of Physical Disability and plans to send her to Spastic Society later on, as an integration measure.

Only a couple of agencies have advocacy activities on-going in the community. One of them does awareness programs on sensitizing communities to disabilities, with a special focus on rural and less educated areas where consanguinous marriage was a common cultural practice. However, this was more by way of information provision in order to ensure consultation for screening and identification of disabled children. One interesting initiative is the self-advocacy forum for adult intellectually disabled in Bangalore city. Facilitated by the KPAMRC, this is a group of individuals with mild intellectual disability and they meet and discuss issues pertaining to the rights of disabled people, such as relationship needs and marriage.

#### Analysis

The understanding of mainstreaming is patchy. Some agencies appear to have a basic level of understanding in that they know that mainstreaming entails sending a disabled child to normal school; other agencies do not even have this level of understanding. Also, while agencies catering to the needs of intellectually disabled children have made some attempts at mainstreaming, agencies that deal with children with pure locomotor disabilities have not attempted mainstreaming processes. However, a second level of understanding that mainstreaming does not only mean inclusive education but that even provision of basic developmental activities including toys and aids in a stimulatory environment is a station in the path of mainstreaming. Thus, mainstreaming starts with ensuring that a child is in a resource center that is located in a normal institution. This approach is provided for under the Inclusive Education Program of the the Sarva Shiksha Abhiyan (SSA) (Dept. of Education), which includes interventions such as identification, functional and formal assessment, appropriate educational placement, preparation of Individualized Educational Plan, provision of aids and appliances, teacher training, resource support.

Regarding advocacy, while there is some awareness of the need for advocacy, there is no planned advocacy strategy for children with disability. There are initiatives such as the National Trust Act and the SSA, these need to be aligned into a more coherent advocacy strategy that individual agencies can adopt and implement within their communities.

#### h) Implications for Training

Agency staff require training in the following areas:

- Conducting systematic developmental and disability-related assessments in the children they serve. This may include assisting some agencies to either follow or adapt existing tools to serve their purposes, so they are able to gather clear information on specific domains of child development and disability.
- Setting objectives and planning activities in clear response to a child's disability and needs; ensuring future projection in care plans and preparing children accordingly with the requisite developmental skills for issues and concerns they are likely to face in time to come; drawing up individual care plans and developing classroom strategies to implement these within or along with larger group activities.
- Identification of common emotional and behavioural issues in children with disability; knowledge and skill on strategies and methods to analyse and manage these problems. A specific area for training would be dealing with sexual behaviour of disabled adolescents.

- How to teach and communicate with disabled children about personal safety issues.
- Training children in adaptive/ survival life skills.

Note: The above-described findings are limited to non-governmental agencies providing disability-related services to children; while some of them might run special schools, not all of them do. Thus, the above findings do not reflect the workings and views of staff/ teachers who work exclusively in special schools.

#### 3.2.4. CCI Category 4: HIV Infected/ Affected Children

#### a) Context of Contact with HIV affected and Infected Children

Agencies report that most children with HIV are referred by the Child Welfare Committee (CWC) or by other government or non-government organizations. Some agencies are well-known to the community so that families bring children directly to them (after which CWC processes are followed to register these children). Such agencies receive a number of children from rural areas like Bidar, Davangere, Koppal and Karwar, where they claim that communities are aware of their services through 'word of mouth'—"when a family knows that their child will be taken care of, they come and leave them here...and then they rarely come to see them; they even refuse to involve themselves in the last rites when the child dies—because of fear of HIV disease."

In some instances, very young children, new born or infants, are also abandoned at the gates of these agencies. These are usually children with disability or infected with HIV. The agencies then inform the police and CWC and act as per the directives of these authorities. As per the J.J. Act, agencies working with children with HIV, are not meant to cater to the needs of children under five years; younger children are meant to be placed in Shishu Mandir or homes that cater especially to children between ages 0 and 6 years. However, due to these infants' HIV status, the CWC often allows these agencies to accept and care for these infants.

Children affected by HIV are also brought to these agencies especially in cases where one or both parents die due to AIDS or when an earning parent is affected and loses the capacity to continue in a job and support the family; financial constraints cause the family to place the child in the institution. One agency that caters to persons with leprosy, disability and HIV stated that they accept all orphans and on testing them for HIV, find that some are infected. This agency also mentioned how they have received adolescent girls who have moderate to profound intellectual disability and have got HIV through sexual abuse. However, they also mention normal girls, without intellectual disability, who are HIV+ and been referred by government homes. The latter group consists of girls who have been trafficked, engaged in sex work (and have therefore been sexualized) or who were rescued from the Devdasi system.

Further, not all agencies provide only institutional care for HIV infected and affected children: some also provide community-based care by connecting families to appropriate nutrition and education programs. In such cases, the child usually lives with the mother (the father may be deceased), and goes to school; the agency helps the family avail of the Rs.800 pension that the Government of Karnataka provides on a monthly basis to HIV affected and infected children, on condition that the child is on anti-retroviral therapy (ART) and usually in case the mother is a widow.

Thus, the age of children infected or affected by HIV ranges from 0 to 18 years wherein infants are usually brought (or abandoned) because they are infected. Older children, between 10 and 15 years are brought because they are infected or affected and parents are unable to care for them any longer. While some agencies care for HIV affected or infected children life-long, others care for them until age 18, after which they are expected to obtain employment and move out of the institution.

#### Analysis

What emerges are two main contexts of work with HIV infected and affected children: one is caring for children within institutions (whether infected or affected), wherein children have been relinquished by their families and have therefore suffered varying degrees of loss and trauma due

to separation and/or death; in this instance, they therefore experience what other normal orphans/ semi-orphans experience due to institutionalization processes. The other context is that of the community, and the needs of HIV infected and affected children who live at home with infected parents or with the surviving parent; this situation gives rise to another set of issues that the child has to face from financial stress to caring for a sick parent.

While both boys and girls are infected (and affected) with HIV through mother-to-child transmission routes, there is a gender difference when it comes to HIV transmission at a later age. Girls, particularly adolescent girls, are infected because of sexual abuse; similarly, disabled girls are even more vulnerable to abuse and therefore to HIV infection. This reiterates the need to protect children, particularly disabled children from child sexual abuse, through personal safety awareness and education methods.

The issue of families and relatives relinquishing an infected child (or even an affected child) to an institution due to their inability to care for him/ her, results in institutionalization of a child, which in itself has certain consequences, such as developmental lags, and attachment and identity issues. However, completely cutting off contact with the child thereafter (due to fear of HIV) i.e. not visiting the child, has longer term emotional consequences for the child (discussed in subsequent sections below).

#### b) Responding to Immediate Physical and Medical Issues

When a child is received at the institution, the first issue that agencies check for is the child's HIV test report and status. If a child has already had it done prior to coming to the institution, some agencies have the test re-done, if it was previously done at a private health facility i.e. HIV test results from government facilities only are accepted. Other agencies are less particular and may accept the test results wherever the test was conducted. If testing requires to be done (or re-done), agencies usually contact Indira Gandhi Institute of Child Health (IGI). Agencies report that all medical procedures, including testing, as per NACO protocols for children with HIV, are conducted/ followed at IGI.

Agencies also have their own medical examination protocols which are not necessarily according to NACO protocols. They all report having sick rooms, visiting doctors, trained nurses and 24-hour ambulance availability. While some agencies have nurses with standard BSC nursing degrees, others have nurses whose with auxillary mid-wives (ANMs) training only from institutions such as CMC, Vellore. However, they all report that their nursing staff are trained in HIV care, including some who have undergone this specialized training at NIMHANS or St. John's Hospital.

According to the agencies, in Bangalore city, ART for children is available only in two hospitals: IGI and Bowring Institute. (Adults may avail of ART in other government hospitals as well). All agencies stated a their preference for seeking care for their children at IGI, where they appeared to be familiar with the Nodal Officer concerned with ART programs and where waiting time was less.

#### **Analysis**

While NACO has protocols for children with HIV, it appears that these are meant for and followed at health facilities only. There are CWC guidelines for running children's institutions; however, these guidelines do not include specific aspects of HIV care for children. Thus, there appears to be no protocol for agencies providing institutional care to HIV infected children --except for the NACO paediatric ART Counseling training manuals (discussed in subsequent sections of this

report)—again, these are training manuals, not protocols that agencies are bound by. There also seems to be the notion that these institutions function like hospices. Thus, the functionaries of these institutions appear satisfied at providing basic care and 'dignity of life' processes. What appears to be missing here are more specific and relevant contexts of care of these children as this does not seem to be the mandate of these institutions.

#### c) Illness and Disclosure Issues

All agencies unanimously reported that they generally do not engage in discussions about the HIV illness nor do they undertake the responsibility of or participate in disclosing HIV status to the children. They tended to be of the view that disclosure was 'not necessary': "We do not need to tell the child...because we want the child to be happy...and we do not want to scare or alarm the child." They felt that if they disclosed HIV status to children, they would 'lose hope'. On the issue of giving hope, one agency also said that they focus on providing responses that give hope to the child: "Next week you will be alright—if you take medicines."

The agency staff were then asked what would transpire in children's mind if the disclosure was not made especially when they see that they are frequently ill and cannot lead a normal life like other children or that they know that have to take medications everyday (ART) i.e. what questions and confusions such issues might create in children's mind. The staff were not able to articulate what these questions and confusions might be. However, they then insisted that 'children know that they have HIV." "They know because they observe and see what is happening around them". These observations ranged from other children being very sick and from some children dying—which in turn has led to questions like "she had a severe headache last night and died today...so if I get a headache will I die to", to which the staff's response has been "no, you will not." Some staff shared other types of responses provided mainly when children ask about why they have to continually take medicine: "I also take medicines everyday for diabetes or blood pressure problems...there are some diseases that you need to be on medication for life-long...like you, I also need to be on diabetes medication life-long." So, staff did state that they provide some response, at some level, if children asked them questions about the disease; this did not include disclosing children's HIV status to them.

All the agencies said that one way in which children learn about their illness is from each other: 'Children of all age group live together. They speak about things openly', said one agency; It is difficult to understand what children discuss in peer group...it can be anything from money, family, food to even larger issues." Although unable to articulate the types of conversations children have and what they discuss or tell each other about illness issues, the agencies were unanimous in stating that children talked to each other and learnt about the illness from each other. Other than these informal conversations, one agency said that they had set up a Bal Panchayat, where children assume roles of leadership; this forum, they say, offers children an opportunity to speak about and discuss their problems, and in this way they also 'come up with their own solutions and alternatives for the problems.'

One agency of the agencies also said that older children know about HIV and therefore younger children, through their interactions/ play with these older children also tend to learn about HIV i.e. children tell each other about the disease. The older children learn about the illness through awareness sessions/ classes that the agency conducts about HIV, mainly on what the disease is about, and how it is transmitted with an emphasis on how children should therefore behave on an everyday basis—this includes how they need to relate to others and how they should report to

the school teacher / agency staff if they have a fall and get hurt. Thus, while no direct disclosures are made about children's HIV status, information on HIV is provided through education sessions.

Finally, agencies said that they 'leave the disclosure issues' to IGI i.e. when children go to IGI for ART and other medical issues, the expectation is that the IGI staff will tell the them about their HIV status and discuss questions and consequences. The perception, as stated, was that the responsibility of disclosure lay with IGI and not with the agency/ institution: "We are just orphanages...IGI is the main part." Thus, staff stated that while they would respond if a child asked a question related to the disease, they did not see a role for themselves in the disclosure process.

## Analysis

Disclosing their HIV status and engaging children in discussions about the illness is critical because, from a child rights' perspective, they are entitled to know. While this may depend on the age and developmental level of the child, the matter has psychological implications beyond the right to know. Unprocessed child interactions, the staff's diversionary methods can often worsen the anxieties and fears of a worried child. Providing half answers or brief responses or generalized sweeping reassurances as a one-off response to the child's questions also does not help. This is especially so because agencies have reported that they find children preoccupied and silent. Agencies are also aware that there is a considerable amount of peer interaction and peer disclosure. Not having knowledge and some level of strategic counselling control over these peer interactions only allow for misperceptions and fears to build.

In the light of this, and considering the position taken by agencies, that they have no role in disclosure, the entire reality of HIV appears to be played out in silence or unprocessed child-to-child interactions. The responses, if any, are often based on either false or unsubstantiated reassurances. As children grow older or as they have more experiences of the HIV illness, they tend to ask more complex and specific questions. If at the level of disclosure itself, there is no response, agency staff and children's interactions tend to be founded on a pattern of non-response. The chances then that later and complex questions will go unattended are greater. This cannot be helpful for the child's psychological well-being. Further, provision of responses to questions about medication pertain to issues of adherence. But information on adherence must follow disclosure and illness facts and agency staff seem to be unable to make the difference (and therefore the connections) between disclosure, illness information and adherence guidance.

It is interesting and somewhat surprising that these institutions which function as places of care for children infected or affected with HIV do not consider disclosure about HIV status as their responsibility. To say that they seek to serve the purpose of an orphanage is not logical because they are also very clear about their target population—they are also categorical in stating that their mandate is to serve the needs of HIV infected and affected children; by deciding to do so, they are acknowledging already that this vulnerable group has clear needs that are different from other normal children as well as different from other children who are orphaned or abandoned. Therefore, to take a position that they are not responsible for critical issues that affect these children's psychosocial well-being is suggestive of acts of omission. It indicates also that these agencies do not function from a child rights' perspective and that they are not aware of the confusions about the illness and HIV status creates in children's minds, and how consequently these impact children's emotional state and behaviours.

Thus, given that they have undertaken the responsibility of care and protection of these children, the perception and expectation that it is IGI's responsibility to engage the child in conversations about illness and disclosure is not tenable. This is further reiterated by the fact that the agencies speak about giving these children love, including and providing for parental/ familial relationships since these children tend to be orphaned, abandoned and are institutionalized: one agency said they encourage children to call the caregivers 'amma and appa' or 'aunty and uncle'. The creation of familial relationships and support sharply contradicts the position and perception that agency staff have taken about illness and disclosure issues. Conveying to the children that there is a relationship/ family context but then not engaging them in discussions and conversations on issues of critical importance only serve to create confusion in children's mind, not only about the illness but also about the nature of the relationship they share with their caregivers.

Awareness and education sessions, as conducted in many agencies, about HIV/AIDS are useful; the information-giving approach in a group setting might help bring some objectivity and neutrality in considering these otherwise sensitive issues and help children understand in general what types of behaviours they should or should not engage in on a daily basis, how to protect themselves etc. However, sole reliance on this method would be difficult. This is because each child receives, processes and responds to information on HIV differently, based on his/her experiences, temperament and cognitive capacities. Each child therefore has his/ her own individual questions and concerns about the illness and these require to be addressed individually, in accordance with his/ her experiences and capacities. For instance, a 14 year old girl with HIV/AIDS acquired through mother-to-child transmission route, where both parents have died and where the girl is grappling with debilitating effects of the illness is a very different counselling context from another 14 year old girl who has a recently acquired infection through an episode of sexual abuse.

Further, relying on children to talk about HIV amongst themselves and transmitting information (unless there a systematic process of peer education has been adopted, conducted with careful adult supervision) could be more harmful than helpful. Conversation between children could range from expression of feelings to support, from queries about the disease to fears and concerns about it. Not only might other children, even if they are older, find it difficult to respond to the concerns and queries of other children but there would also be the risk of incorrect responses provided, causing further damage. Bal Panchayats may serve the purpose of discussing and addressing general problems that children in institutions face, but these are unlikely to be deeply personal issues that children feel troubled by, and they are hardly likely to entail disclosure-related issues. In any case, in a situation where adults/ caregivers do not have the capacity, skill and at times the desire to provide appropriate and sensitive responses to children, one can hardly pass on this responsibility to the children.

In summary, the discussion on illness and disclosure highlights the following issues:

- The view that it is not necessary for children to know versus the right that children have, to know about their HIV status and the illness.
- The issue of 'if they ask, I will tell' which means that 'if they do not ask, I will not tell' or that 'there is no need to tell'.
- What caregivers can tell children i.e. different levels of responses, depending on the child's question and concern as well as on his/her age and cognitive capacity.
- The balance between answering a child's questions accurately and also ensuring that the child does not lose hope/ is not overwhelmed by HIV and its possible life consequences.

#### d. Emotional and Behavioural Issues

According to one agency, since most children they care for are from rural areas, their early environments have not been conducive to them developing an interest in academics. Therefore, lack of interest in studies is a common behavioural issue they notice. Other agencies also corroborated this, saying that children have poor attention and concentration with regard to academics.

However, attention problems are not related to academics only—the staff state that this applies to any task at hand: "sometimes we ask them to go and bring something... and then half way there, they forget what they were going for...they are in their own world...and we cannot understand it." They stated that children tend to be withdrawn, isolated and 'in their own world'. It was also reported that children tend to be 'moody and sad' and they 'sit alone...they may get up and play for a while and then go back and sit alone.' The staff were not able to attribute causes to these emotional and behaviour problems and when specifically asked whether some of it could be to do with illness and disclosure issues, they were unsure. One agency spoke of the 'internal struggle' of the children and the staff's difficulty in understanding what the struggle might be or the concerns really are. Other agencies did not articulate this difficulty or the need for understanding children's concerns.

Other problems stated were temper tantrums, anger, fights and truancy both in the context of school and the institution. A major concern stated by one agency was children's anxiety about the future. This was corroborated by another agency who said that there appeared to also be a gender difference in how this anxiety was experienced. While the boys seem 'more bold' and are rarely depressed or 'generally ok as long as they are engaged in some activity', this is not so for the girls who worry that "no one will marry me when I grow big." Girls are particularly concerned about family traditions and how they will not be able to experience 'normal family life.'

Another issue that was reportedly common among children in the institutions was "these children always think they are underprivileged". The children feel that "other children have homes and parents..." Some children are greatly affected by the lack of visitors to them, for, these children crave family visits. In this context too, girls tend to feel more anxious than boys.

No agency had experienced children committing suicide (except one where a child attempted suicide), nor do they have suicide counselling procedures or protocols. Again, one of the agencies reiterated that 'they give hope' and tell the children 'they are worth it'.

When asked how agency staff respond to these problems, some agencies were unable to discuss any sort of response. One agency stated that when children appear depressed and isolated, staff try to talk to them and ask them to bring some art and craft work to do. Another agency used the example of a boy who repeatedly ran away from the institution to explain how they responded to his problem. They said that the child had been admitted to NIMHANS and acknowledged that the doctors had been good to him. But at the end of his admission there, the agency had decided (irrespective of the impact of the treatment received at NIMHANS) to try other measures as an 'experiment'. They said that this was based on the fact they believed that the children 'did not need any more sympathy' although they maintained that they try to solve their behaviour problems 'with love and concern'. The reason for the child's repeated truancy behaviour was not clearly articulated by the agency staff—they said that 'it had something to do with' the child's wanting to go back to the village and deal with his uncle who had usurped some

family land. They said that they made a decision for the child to be sent to one of the agencies institutions in Tamil Nadu i.e. 'to completely remove him from Karnataka' and have no contact with NIMHANS or places in Karnataka. Apparently this strategy worked as the child now takes care of the garden at the institution he was put into and was perfectly happy.

Only one agency articulated some strategies of response used. They also qualified them by stating that 'we give no mental treatment'. First, their response is based on the premise of 'no sympathy, only love' principle. Second, they said that they get the children to learn a number of activities such as carpentry and gardening, specifically being involved in hybrid flower cultivation and supply to various places. Third, that they do not believe in restricting children to any space and that they allow them the freedom to go anywhere they like, so that they have exposure to different places. In this regard, they do not ask how many times a child may have run away either. They also get the children to go back home during the summer holidays, so that they reconnect with their families and relatives.

Another agency spoke about how dance therapy is offered to the affected girls. However, the agency representative was not convinced of the effectiveness of this strategy in combating feelings of anxiety and depression in the girls: "their mind is diverted at that moment—when they dance. But later, at night, they are depressed again."

When asked how agencies respond to issues of loss, grief and death, particularly in the face of mortality, agencies were varied in their responses. One agency said that they do not expose the death of a child to other children; that is, then a child is seriously ill, he/she is shifted to the sick room and when the child dies, other children pay participate in prayer—also the way in which they are informed about the death. Only older children (adolescents) may be present during the last rites and rituals. Another agency said that all the children at the institution are asked to participate in the burial/ last rites rituals and that a religious approach is used in that they get children to understand that there is life after death.

#### Analysis

Where agencies work on the basic premise of providing dignity and love to children, basic requirements may be met with. However, there may be an assumption, here, that is simplistic in that love can take care of any problem or emotional need. There is another angle to this: those religion-based agencies who go through a more reflective experience of not understanding the complex situation of the child ('the internal struggles of the child') then run the risk of believing that their love was not good enough. Thus, more 'professional' counselling based approaches are required to fathom the workings of an HIV-AIDS affected/ infected child's mind.

It is evident from the discussion that agencies have little understanding about the underlying causes of emotional and behavioural problems that HIV affected or infected children may have. The knowledge that there are causes that pertain to the illness (including disclosure issues), such as anxieties and hopelessness about the future or that there are other issues such as experiences of loss, grief and death, that children have been through because of the HIV illness and or because of being institutionalized, is not apparent in these agencies. In fact, one agency, in speaking about their experience with a child with truancy behaviour acknowledged that they were not entirely clear about the child's reasons for practicing this behaviour.

While agencies, because of their religious beliefs or otherwise, have different approaches to how they expose or inform the children in their institution about a child's death, there appears to be no

practice of supporting children to grieve or in responding to fears and anxieties that may arise from witnessing/ experiencing the death of a peer. While prayers may serve the purpose of information about an event and allow for some vent to feelings of sadness and worry, there needs to be more direct discussion on HIV and related significant issues. When even normal children have queries about death, HIV infected children who are more exposed to death, will have additional and more in-depth queries about it.

Thus, it appears that some agencies do not have a culture of conversation with the children they care for—a culture of conversation entails encouraging a child to express concerns, engaging the child in explorative dialogues about it and providing responsible and carefully considered responses to the child's queries and concerns. Worse still (as in case of one agency), some staff do not seem to think it necessary to understand the cause of a child's problem behaviour. Finally, they do not have the skills or a repertoire of strategies to systematically address various types of emotional and behaviour problems.

Furthermore, use of anthroposophic methods (carpentry and gardening activities) or community rehabilitation strategies (family time for children), are not founded on a clear conceptual understanding of children's emotional needs or problems; they are merely implemented with loose objectives, as manifestations of 'love, not sympathy' ideology, with no recognition that these strategies do indeed constitute important modes of 'mental treatment'.

#### e) Developmental Impact of HIV

Agency staff were engaged in discussion about the key child development areas, namely, physical, cognitive, social, emotional, speech and language development and asked about their awareness of these issues, specifically how HIV impacts children's growth and development. The agencies responses included 'weak muscles', 'poor body immune system and poor stamina' (how HIV infected children get tired more quickly than other children), 'activity levels keep varying' and 'poor attention and concentration'—in this regard an example was given of a child who wished to become a doctor and who scored 98% in her 10<sup>th</sup> grade exams but who was unable to maintain her academic performance in college thereafter because 'no matter how much she studied, she complained, she was unable to recollect anything.' The agencies said that many of these issues were due to the side-effects of ART.

#### Analysis

It is evident that agency staff have no systematic understanding of key areas of child development and that therefore, they have no framework within which to analyse children's developmental needs or problems. Currently, there is only a hazy idea that ART causes memory problems and physical weakness. They were also unable to think about the developmental needs of younger children i.e. children aged 0 to 6 years, the critical period when children acquire basic, important abilities and functions in the areas of physical, social, cognitive, emotional and speech and language development. Consequently, they were unable to observe the deficits that HIV infected children tend to suffer (due to slower or impaired brain development) and as a result do not know about the importance of early stimulation; they are not aware that increased early stimulation i.e. greater than would be provided to normal children, is essential to aid the growth of HIV infected (and affected) children. Of course, the recognition of developmental needs for other age groups, above age 6, is also important for continued growth and maintenance of a normal developmental trajectory for HIV infected children—but this awareness was also lacking amongst the agency staff. Their perception of responding to children's growth and development needs of

HIV infected/ affected children is limited to provision of adequate nutrition as required for children to be on ART.

#### f. Dealing with Stigma and Discrimination

In case of institutionalized children, their primary contact with the outside world is through school. Some agencies have made persistent attempts to send their (HIV affected and infected) children to normal schools. Their experiences in this regard have not always been easy. One agency mentioned having shifted their children to 5 different schools because the school refused to keep them. The agencies state that it is not the school that is the greatest problem but other children and their parents, who discriminate against HIV infected children, who are fearful that the disease might be transmitted to them. Parents threaten to withdraw their children from school if HIV children continue to be present in class. This occurs more in private schools.

Agencies have, however, found that their children suffer less stigma and discrimination in government schools (and also in schools run by religious orders). This is because the school is not under pressure from parents wanting to withdraw their children, as these families come from lower socio-economic strata of society and have a more limited choice in terms of the schools they can afford to send their children to.

Agencies state that they generally inform the school about children's HIV status because these children require special care and alertness on the part of the teachers—such as when they fall down and hurt themselves. That these children are frequently ill and unable to do homework is another reason schools and teachers need to be cognizant and understanding of HIV infected children's problems. One agency has also offered training for school teachers to enable them to be aware of HIV infected children's needs. Some agencies, however, have decided not to expose their children to stigma and discrimination issues by providing for their own schools and institutions.

In order to circumvent the problem of outside placement in a school, one agency runs a school within its own premises, affiliated to the state-board. All the children within its institution attend this school, thus not having to contend with stigma and discrimination issues.

As mentioned elsewhere in this report, one agency engages in community reintegration activities such as getting children to go home during holidays so they can re-connect to and be with their families and relatives. When asked about how the immediate community (surrounding neighbourhoods) perceive these children, agencies said that they had not experienced any stigmatization or discrimination by them nor had they conducted any awareness/ sensitization programs for them. In fact, families from nearby communities come to these agencies/ institutions to celebrate birthdays and special occasions. Communities are thus perceived by agencies as being more accepting of HIV infected and affected children than schools.

#### Analysis

Interestingly, agencies made no mention of the families or extended families of HIV affected and infected children in the context of stigma and discrimination, although earlier they stated that several of these children have no visitors or family connections due to families' fear and discriminatory attitude towards those with the disease. That the community does not appear to discriminate against these children cannot really be inferred from occasional celebrations located in the institutions; this is because such occasions do not entail extensive contact with the children. This would also explain why schools are perceived as being more stigmatizing and

discriminatory—teachers and other children are in close proximity to HIV infected children for continuous and extended periods of time, thereby creating cause for more concern. In the light of this, awareness and sensitization of teachers is a laudable effort. There is also little evidence of agencies using advocacy strategies within the community, including awareness, to actively further the cause of these children.

As previously stated, while some agencies practice strategies for community reintegration, there appears to be a limited conceptual basis or understanding of this. Also, these are occasional and very time-bound opportunities for children to engage with the outside community. This compromises socialization and affiliation processes and skills. Therefore, providing planned opportunities for these children to engage in day-today social interactions outside the institution is an important intervention for community reintegration and development of social skills and for reduction of social stigma and discrimination.

#### g) Recommendations for Staff Training and Capacity Building

- Building an understanding in agency staff that HIV care is not just about providing basic needs and that institutional care for HIV infected/ affected children involves larger mental health issues.
- An understanding of child development and how HIV impacts children's neurodevelopment; consequently, in addition to ART and nutrition, develop knowledge and skills to be able to maintain children's developmental trajectories (especially speech and language, social, cognitive, emotional development—not only focussing on physical development and well-being).
- Getting agencies to acknowledge/ agree that they have a role to play in illness and disclosure issues i.e. that discussions about illness (including impact, consequences and ART adherence) as well as disclosure need to be done using systematic methods.
- Developing a stronger understanding of the ethics involved in caring for HIV affected/ infected children—including disclosure, professional ways of creating familial types of support, and re-examination of use of religion in the name of counselling.
- Role (and appropriateness) of child-to-child methods/ peer education in HIV illness issues.
- Understanding individual children's realities rather than a 'one approach fits all' method.
- Skills for identification of emotional and behavioural issues and the nature of their relationship to the child's HIV illness.
- Skills for systematic use of methods to address emotional and behaviour problems.
- Skills to support children in their experiences of loss and grief traumas.

#### Nodal Officer, Indira Gandhi Child Health Institute

With a view to corroborate some of the information provided by the HIV children care institutions, primarily information related to disclosure issues, the Nodal Officer (NO) at Indira Gandhi Child Health Institute was briefly interviewed.

#### a) Initial Physical and Medical Care Provision:

The Nodal Officer provided additional information on first level care for physical and medical issues, stating that IGI provided only first-level testing for children with HIV i.e. a single test is conducted to check for sero-positivity. This includes pre and post-test counselling for parents and caregivers. If the test results are positive, then children have to avail of subsequent tests at other government health facilities/ centres, such as NIMHANS (and others), at which time, pre and

post-test counselling is provided again to parents and caregivers<sup>15</sup>. As per NACO guidelines, consent for testing children (individuals under age 18), is provided by parents/ guardians or in case of institutionalized children, by wardens; there is no process for obtaining children's consent prior to testing for HIV. For those children who test positive, ART is obtained at IGI as well as other government institutions such as Bowring Institute and Vani Vilas Hospital. Thus, the knowledge that the agencies have, that ART care for children is provided only in two government institutions in Bangalore city, appears to be incorrect.

#### b) Illness and Disclosure Issues

According to the NO, the NACO guidelines are not clear about when/ what age to disclose HIV status to children. In general the assumption is that disclosure about the illness/ status may be made to children when they are about 10 to 12 years of age; however, western guidelines state that the process of disclosure can begin as early as when children are 6 to 7 years old.

In addition to the decision about what is an appropriate age group to disclose to, the NO stated that there were problems and controversies about the term disclosure i.e. what it means or entails: "What is the definition of disclosure? Just to say you have the disease? No...it is a process."

In the backdrop of the above issues and the fact that HIV counsellors have limited counselling skills (discussed in detail in the next sub-section), IGI's ART staff and counsellors approach the illness and disclosure issues by first finding out (asking) what children know or have already been told about their illness. They build on this knowledge by providing additional information on illness issues, including what children should do to protect themselves. In IGI staffs' experience, most children know how HIV is transmitted and that they need to be on continuous medication. However, they tend to know less about the consequences of HIV (especially long term consequences) and therefore about how to take care of themselves. According to the NO, as the agencies also said, children already know they have HIV because 'someone would have told them' or 'they know from each other' i.e. they have vicariously picked up the knowledge that they have it; their HIV status has often not been formally disclosed. This fact may also explain his experience, children in institutions are 'more open and accepting of their HIV status' than those living in the community with their parents.

However, even if children have come by the knowledge that they are HIV+ from other sources, even at health facility level, possibly due to the limitation of skills of the counsellors, there is, like in the agencies/ institutions, a culture of skirting the issue where children are concerned; a discomfort and hesitancy that pervades the health system also. This is also perhaps reflected in the fact that the NO mentioned that 'children do not ask too many questions when they come [to the facility for ART]—they find it hard to ask." He also said: "we ask...why have you come here? What do you know about the illness? But it takes a lot of time for them to open up..." Children find it hard to ask questions because they have already sensed the silence and discomfort that surrounds the illness issue.

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<sup>&</sup>lt;sup>15</sup> The reason HIV test results from private healthcare facilities are not accepted are two-fold: i) private facilities often do not follow NACO guidelines about pre and post test counselling; ii) they may therefore also do only partial testing and declare results based on one test only—such as Elisa test—when NACO protocols ask for 3 tests to be done to confirm HIV.

Other than the disclosure/ counselling skills of the health facility staff, there are logistical issues that make it difficult for them to provide extensive information and counselling on the illness. This is because each child visits the health facility about once in two months only and the time spent with each child by the facility staff is extremely limited i.e. it does not allow for extensive discussion. This goes back to the issue that disclosure is a process, as stated by the NO, and not a one-off information provision session. Furthermore, the NO said that there is a need to build rapport with the child to be able to engage him/her in disclosure processes. Time constraints make is difficult for health facility staff to build the necessary rapport with each child and consequently, do not set a comfortable context for disclosure and in-depth discussion of illness issues. Where there are some long-standing staff, with particular personal interest in children, such rapport building has been possible to some extent. Such staff are very few; and staff turnover at the ART centers is very high, thus not allowing for continuity and rapport building.

Furthermore, as per NACO guidelines, health facility staff are not responsible, or not solely responsible for disclosure processes. The guidelines state that parents and guardians should disclose HIV status to the child or in case there is a counsellor, they should be present with the counsellor, who can assist them in the disclosure process. In case of children in institutions, the institution/ agency staff (in the absence of parents) therefore, are responsible for disclosure issues. Consequently, current perceptions of the agencies, that they are not responsible for disclosure and/or that health facilities such as IGI are responsible for these functions, are completely erroneous.

Given the NACO guidelines and the logistical constraints of the health facilities, the NO said that over the years, he has constantly advocated for HIV care agencies/ children's institutions to appoint counsellors to implement disclosure and engage children in discussions about the illness; in case they cannot appoint counsellors, he said, agency staff must develop the skills to play this role themselves (and that health facilities such as IGI would be willing to support these initiatives).

#### c) NACO Guidelines for Paediatric HIV Counseling

NACO has developed a set of Paediatric ART Counseling Training Modules—a Facilitator's Guide and Participant Guide form this two-part manual. However, despite the existence of this manual, the NO claims that paediatric counselling for HIV is not very advanced. In his experience, many of the training modules are extremely theoretical; as a result, counsellors in the health facilities do not feel equipped to engage with HIV infected children i.e. they still lack the skills to do so.

It appears that HIV care agencies, while they are aware that NACO guidelines exist for responding to children infected with HIV, use these guidelines to a very limited extent. Their position that these guidelines are only for the use of health facilities is erroneous as the NACO Paediatric ART Counseling Training Modules clearly state that they provide 'practical skills and tolls to the counsellors and other care providers working with HIV infected children and their families.' These counsellors and care providers are certainly not limited to government health facilities who make available testing and ART facilities; and they certainly they extend to institutional/ agency staff who are providing round the clock care to HIV infected children. That the agencies/ institutions are not aware of this is clear from the position they have taken on issues such as disclosure, which are discussed in these training modules (as part of counselling skills) and which must therefore, form one of the important responsibilities of caregivers within HIV infected children's institutions.

#### 3.2.5. CCI Category 5: Children with Gender and Sexuality Vulnerabilities

## a) Background and Type of Targeted Children

The agencies represented at the assessment and sensitization workshops worked in the area of gender and sexuality in the context of four types of children: children of devadasis, urban/homeless/street children and children who were trafficked for sex work or other purposes of child labour.

Devadasi<sup>16</sup> children: While conducting a study about violence against women in Karnataka, the agency concerned came across the issue of devadasis. In order to address devadasi problems, a network of NGOs was formed between Karnataka and Andhra Pradesh. During the course of their work with Devadasi women, the agency realized the adverse impact of the devadasi system on children of devadasis (mainly girls), including the risks of them being drawn into the system too. In response, the agency started a program, involving institutional care and protection for children of devadasis. Girl children are drawn from 14 districts in Karnataka (such as Raichur, Bijapur, Belgaum, Koppal etc) where the devadasi problem tends to be concentrated.

In the devadasi system, the mother (devadasi) is recognized as the head of the family. Children may or may not know who their fathers are, depending on if they meet them or not. In cases where the mother has a partner for a life (a married male who has a family of his own), children know who their father is but they have no relationship with them i.e. there is no father-child relationship; the man usually visits the mother at will, mostly at night, therefore, having nothing to do with the child. Where the mother's partner discontinues visiting her, the child may not know who the father is. Thus, devadasi children do not know paternal love as they have no relationship with their fathers. They are told that he 'comes for the mother only' and they know that 'my mother is a devadasi'. The agency did not know of any instances where the mother's partner may have abused the child. Children have very limited contact with their father.

In devadasi families, the girl child is treated as the son, and she is expected to look after the family. 'Dedication of a girl child' ranges from when the child is 5 to 6 months to when she is older. However, she the partner is permitted visitation rights when she attains puberty. In families that have not had the devadasi tradition previously, the reasons for it to begin, or for them to decide to 'dedicate a child' are usually to do with illness of some family member—in the belief that the dedication of the girl child to God will cure the illness. In some cases, girl children with disability are also dedicated because of the fear that they will not be able to get married. But most often the devadasi system exists in families that have followed it for generations i.e. grandmothers are devadasis, followed by mothers, and consequently, the girl child born to her is dedicated. Thus, girl children of devadasis are at risk of being inducted into the same system, in order to continue it.

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<sup>&</sup>lt;sup>16</sup> In South India, a devadasi (Sanskrit: servant of deva (god) or devi (goddess) is a girl "dedicated" to worship and service of a deity or a temple for the rest of her life. The dedication takes place in a Pottukattu ceremony which is similar in some ways to marriage. Originally, in addition to taking care of the temple and performing rituals, these women learned and practiced Sadir (Bharatanatya), Odissi and other classical Indian artistic traditions and enjoyed a high social status as dance and music were essential part of temple worship. Today, the devadasi system has evolved into open prostitution in many Indian States except in a few pockets where it still flourishes under the guise of 'dedication to Yellamma.' In Karnataka and in some parts of the Maharashtra-Karnataka border, the system continues whereby trafficking is induced and implemented by the immediate family of the girl. The difference between the commercial system of prostitution as it exists everywhere and the devadasis who are now prostitutes, lies in that while the former is purely commercial, the latter is perpetuated in the name of Yellamma though the motivation is the same – survival.

Traditionally devadasis had a high status in society because the system was practiced by what were considered as upper caste families. However, over the years, as the system became implemented through prostitution of women and trafficking of girl children, it became largely a system practiced by what are considered as lower caste families—who were frightened into dedicating a girl child and threatened with continuing family problems and other dire consequences if they did not. These so-called lower caste families are usually families with low socio-economic and poor education status. Consequently, devadasi children come from disadvantaged backgrounds and tend to suffer considerable stigma and discrimination issues.

Street and Working Children: Other agencies work with children drawn from a range of vulnerable backgrounds, including:

- children who engage in beggary and other forms of child labour;
- children who are trafficked for sexual and other labour purposes, (and brought through raid and rescue operations);
- children who have been physically or sexually abused within their families (and who either run away or are not wanted by their families);
- urban/ homeless children who engage in substance abuse
- urban/ homeless children who have dropped out of school
- orphans and semi-orphans
- runaway children
- children of parents who are in prison
- children of women who have undergone experiences of domestic violence/divorce (and who live with their mothers for whom the agency provides care)

According to the agencies, most of these children have been raised in homes where there is alcohol abuse by one or both parents/ caregivers. While some agencies (such as those working with street children or with the urban homeless or children in difficult family contexts) agencies) work with boys also, they state that their focus tends to be on girl children because they have found that girls are more vulnerable to trafficking and various other forms of abuse. They acknowledge that boys are also subjected to sexual abuse and trafficking and are also impacted adversely by neglect and other family circumstances; however, they stated that they focus more on 'rescuing and helping girls' because 'there is still a perception that a boy will manage life somehow and we don't have to worry too much.'

#### b) Context of Contact

The agency working with devadasi children collaborates with other NGOs working with devadasi women to identify devadasi children at risk; those NGOs, during the course of their work with women, identify devadasi children and obtain family permissions and refer the children to the agency concerned with providing care and protection to the children. CWC has a role in this process.

While some agencies focus exclusively on care and protection of girl children, others care for both boys and girls in separate facilities. For instance, one agency runs two (separate) institutions exclusively for girls, one to cater to the needs of the urban/ homeless girls and the other to look after girls rescued from sexual trafficking. All agencies (except one which only receives CWC referrals) have direct field operations through which they identify or come into contact with the children they work with. BBMP areas where vulnerable urban poor live are mapped out and field workers identify children who are abused/ in difficulty, either directly or by asking other families within that neighbourhood about any children/ girls they know of who are in a difficult situation. They then meet the child and family, convince them to join their institution, telling them how they will receive shelter and basic care as well as education.

Agencies that engage in raid-rescue operations have field staff who are deployed when there is a reliable 'tip-off' about where children have been trafficked. These staff usually work in collaboration with the police system and a planned raid and rescue operation is launched. This process is not without its unpredictable drama. A part of the challenge here is to minimize the unsettling components that this process has for the children. The time available for these operations is short and a lot of care has to be taken in this compromised time to explain to the children what is happening and make them comfortable about the legitimacy of their rescuers. This process is complex because trafficking itself has occurred through subterfuge and manipulation. Therefore, children have serious trust issues and it is difficult for them to be convinced of the good intentions of their current rescuers. The agencies go through the CWC processes after rescuing or identifying the children concerned. But like other agencies, they also receive referrals from the CWC, who in turn receive affected children through the police or ICPs systems.

#### c) Responding to Immediate Issues

Initial issues faced by CCIs are about children not wanting to stay, especially boys who tend to run away. When children first arrive, they find it difficult to adjust to a new place/ situation and so, tend to be less cooperative. In cases where families force children to be in the institution and children do not wish to be there, they have a more difficult time with the initial adjustment.

However, there are also instances where children are willing to join the institution and the adjustment has still been difficult. For example: a child used to earn a living (through beggary) for her mother and her mother used all the money for alcohol; CCI staff convinced the child to join the institution and the child was willing to do so, and even settled down. But when her mother visited her, the child wanted to go home, despite knowing the problems with that. As one staff stated: "No matter what the institution provides...no matter what we do, or what we give, they want home things...they value even a tiny pin if it is from home," meaning that children always prefer to be home, no matter what difficulties may be associated with the home situation.

Devadasi children often have particular trouble leaving their grandmothers, whom they are very much attached to, when they have to leave home and join the institution—this despite knowing the institution staff, whom they are familiar with because of the staff's presence in the community and having met them before arriving at the institution. Some children tend to run away from the institution to return home while others use a range of methods to try and leave the institution and go home: they create scenes of protest and upset in front of guests, hoping to embarrass the agency and convincing the staff to send them home; there have been some cases where girls have coloured their panties, pretending that they have begun to menstruate, because they know that they would have to be sent home for the rituals and ceremonies performed at the time of menarche.

Another issue is of children transferred from state run institutions. NGOs have particular problems getting children who have been shifted from State Homes (government institutions) to settle in because these children have had bad experiences with the staff there and have already therefore may view life in an institution, even the new one, negatively or with great trepidation.

Children who are rescued from trafficking or situations of sexual abuse arrive in a state of trauma. They often wish to speak with no one, particularly male staff, and they also do not easily tell the truth about where they come from i.e. where their homes are. In some instances, girls who have been sexualized also feel the sexual urge and during such times 'they behave

differently...they giggle and run around the home, appear very distracted and not participate in the institution activities'. CCIS staff find each of these situations difficult to handle.

CCI staff have made attempts to address some of these initial issues such as creating a feeling of 'home' at the institution—many institutions are not called 'hostel' but referred to as 'home. Some agencies provide a 'Welcome kit' to each child who arrives at the institution—this kit consists of clothes, toiletries, books, a bag and other personal items. Most agencies also form a welcome committee of children, who are prepared for the new arrival, and who greet the new comer with ceremony.

#### Analysis

An induction of the child, in more structured ways, so the child anticipates different types of pressures in the Home and is able to respond/ adjust is an important procedure to follow. This has two critical bases:

- i) Despite a general conceptual understanding of counselling processes, the actual unfolding of this process becomes a question-answer-advice session. What are missing here are preparatory processes that address hesitancies that a child may have (for example: to say 'I know that you have gone through a lot. Sometimes it is difficult to talk about these experiences easily. However, I would like you to know that we have come across many children whose experiences are similar to yours and over a period of time, as you become more comfortable, it will be easy to discuss many questions you have in your mind.')
- ii) Despite the knowledge that these children go through experiences centred around sexuality/ trauma, actual counselling interactions tend to skirt these issues peripherally. General reassurances and future planning are focussed on but narratives and disclosures on the core issue of trauma are less discussed because of the mutual discomfort that they generate.

While sexual abuse and trauma may be the primary issues, there are sub-contexts to this: children with gender and sexuality vulnerabilities may be child labourers, divorced family contexts, devadasi families, alcohol problem contexts, runaways, HIV infected/ affected or trafficked. They may have suffered single or multiple episodes of sexual abuse and trauma, become pregnant, and even delivered a baby. Thus, the context in which sexual abuse and trauma occur are varied and each of these sub-contexts present their own issues and q1challenges, which have to be dealt with in addition to the trauma of sexual abuse. This calls for additional skills to carry out a level of depth work focussing on healing from trauma. In complex situations like this, generic counselling interventions will not be sufficient.

## d) Establishing Rapport and Relationship: Eliciting Trauma Narratives

When asked how agencies establish rapport and relationships with children, and how they elicit children's trauma narratives, the staff said that children detest the word 'counselling'. They often refuse to come for (what they perceive) as counselling. Children's responses to staff requests are 'Oh, you have to do counselling for me now? Ok, so you just want to hear my story again...' The staff attribute these responses to children being tired of being subjected to questions over and over again about their past lives by the police and legal systems as well as other staff in the home, especially in the initial stages or soon after their arrival.

In fact, all agency staff agreed strongly that initially most children do not tell the truth about their past lives or experiences. This is due to fear and their lack of trust in agency staff. This lack of trust may continue for a period of weeks or months (in come children, even for a year or two) and is manifested not only in not telling the truth but also on children leading staff to wrong locations

when they go in search of their homes and families. However, upon arrival at the destination (often after extremely long car journeys) children frequently say 'this is not my home town'. The staff say that when children run away from home (or are taken forcibly from home), they have developed a geographical map in their minds and are able, when they later accompany staff to guide them to their homes, to identify various places enroute. The staff feel that children deliberately guide them to erroneous locations because they have enormous trust issues—especially because persons who have taken them forcibly or with promises of education and employment have then trafficked them; later on, when the children have a rapport with the staff, they guide them correctly to their home towns.

As a result of this lack of trust, agency staff claim that it is very difficult to create a formal counselling space where children can tell their stories and narrate their trauma experiences. However, they also believe that there are other reasons for this. Some of these include: 'children feel that people who may not have had their difficult experiences will not understand them', 'they have decided not to talk about their past and pain because they have decided to leave it and move forward', and 'there is some self-realization that I need to think about the future.'

Thus, the staff say that they leave children to decide 'when to tell, how much to tell and what to tell' by 'giving a lot of time' and 'creating the space' for children to feel comfortable and be able to tell. This may be done through occasional conversation and exchanges during daily activities or in informal spaces in the home, such as sitting on a bench in the garden and 'asking one child' and 'then all others come and tell that this also happened to me'. 'When we accept and listen without judgement, they tell on their own...that is, when they trust and believe in us.' The staff stated that they had had no training in trauma work and how to approach it with a child—they have, so far, been using their instinct, experience and observation to elicit information and respond to children.

#### **Analysis**

That children in these contexts have 'counselling fatigue', is completely understandable-especially since they undergo police and CWC procedures, and then assessment when received in the institution to which they come, with each systemic component asking them for information and offering various types of assistance. That following their family/ home and societal experiences they have difficulty trusting anyone is also natural. However, these cannot be the reasons for not broaching trauma issues and initiating discussions with children.

Given the types of experiences that children in these agencies have come from, mainly trauma and abuse, there is a need to i) understand how these children have been impacted by their trauma experience, in terms of their developmental trajectories, particularly social, cognitive and emotional development; ii) help them process their trauma experiences and overcome any negative impacts they may have suffered. Such processes require developing a rapport and relationship with the child, establishing the context of each individual child's problem in order to elicit his/ her trauma narrative.

Further, while the child's readiness to talk about her issues is essential to the process and needs to be respected at all times, there is a spectrum in terms of the time-lines and ways to begin addressing trauma issues: at one end of the spectrum is to insist that the child talks about her trauma experiences right off, as soon as she arrives at the institution, almost amounting to haranguing a child who may not be ready to share her problems as yet; at the other end of the spectrum is waiting indefinitely for the child to bide her time and talk about her trauma

experiences. Neither extreme is in the interests of the child's well-being. The first could only make the child angry or more afraid and less willing to share; the second could have two detrimental effects: a) it places the onus of taking the initiative on the child and this, is challenging for individuals having suffered trauma, due to the difficulties associated with verbal expression of trauma (not only for children but even for adults); b) when much time goes by with 'nothing said' or 'things waiting to be said', it is important to remember that the child is pre-occupied in rumination and cogitation; receiving no guidance in this process, she continues to have unanswered questions about what happened to her or she tries to answer these questions/ draw conclusions on her own. These may frequently not be correct or helpful, thereby only exacerbating her fears and anxieties, which in turn have adverse impacts on her emotional states and therefore on her behaviour patterns, including on her daily functioning.

Some of the staff's positions about indefinite time requirements or their concerns about children's counselling fatigue, it is suspected, may come from their own discomforts and lack of skill in broaching conversations about difficult issues such as trauma. Thus, they require capacity building in addressing trauma issues, including how to approach the issue, how and when to talk about it, what methods they can use and finally, how to respond to the narratives that emerge, in ways that enable children's healing and recovery.

#### e) Emotional and Behavioural Concerns

Broadly, staff observe many sex and sexuality-related problems in the children and they find it difficult to respond to many of these problems. Other problems they describe relate to anxiety, anger and attention-seeking behaviours, which are not uncommon among institutionalized children.

Girls rescued from situation of intra-familial abuse situations, often sexually abused by their fathers, and at times, pregnant, suffer various types of emotional and behaviour problems such as bed-wetting, refusal to bathe, eat, or play/interact with others. One agency reported that most girls above age nine, who come to institution, have suffered sexual abuse in some form or otherat least by way of inappropriate touch, or they have been witness to sexual activities frequently due to alcohol problems in the family. In such cases, children do not think of sex as being 'unusual' and they are already sexualized, either through abuse within the family or through sex work. Some children may also be HIV+.

Dealing with girls with extensive sexual experience, such as those who have been trafficked and engaged in sex work, has been difficult for staff. These girls have times when they experience desire and sexual arousal and during this period, they get angry quickly and start fights with others or they tend to threaten suicide i.e. there is a considerable degree of emotional lability. Some girls take younger girls to lie down with them or have a bath with them as they have no other opportunity for gratification.

In addition to sexual abuse, staff also have difficulty dealing with normal adolescent sexuality issues. They report that girls 'have feelings of attraction' evident when they when there are male visitors/ coordinators and the girls 'talk excessively to them.' The staff's theory is that the girls behave this way as 'they not had father's love'.

The issue of feeling the need for a father is a common one amongst devadasi children also. These children ask male coordinators 'can we call you father?' and insist on doing so, hoping to create that relationship, and get that affection. The issue of paternity keeps arising in their lives

through other systems as well—when they go to school and have to fill forms, they are required to write their father's names. Some children write 'anjanaya' for their father's name—as per devadasi system. Sometimes children drop out of school because they are asked about their fathers and feel very pressured. The school is asked by the agency not to pressure child and to understand that these children's fathers do not really exist, for all practical purposes; however, the difficulty continues and the emotional need that children feel, for a male parent, remains.

The other context in which the issue of paternity arises and affects children's emotions is in case if agencies sheltering women who have suffered domestic violence and are divorced from their husbands. These women's children live with them and the mothers train their children not to tell/mention their father's name; in fact, they tell their children that their fathers are dead.

Another common problem is school refusal, usually accompanied by psychosocial complaints (used as a reason to avoid going to school). The reasons, according to the staff, are: for some older children, this is the first time they are going to school and they dislike being put in a lower grade, and having to sit/ interact with younger children; they find it hard to contend with peer pressure and academic performance issues—tests/ exams are another time where psychosomatic complaints occur, including menstruation and menstrual pains.

Other examples of emotional and behaviour problems were also mentioned by agencies: a girl writing on the wall with menstrual blood, cutting strips of soap and inserting into her vagina, tearing school books and putting shreds into her bag day after day, possible instances of anger and perhaps in the backdrop of sexual abuse.

#### Analysis

There is a tendency to respond to emotional and behaviour problems with reassurance or admonishment. While there is a nascent recognition that these problems are a consequence of a primary experience/ trauma, this primary cause is not adequately dealt with in counselling processes. The staff experience great consternation at the extent to which sexuality and sexuality behaviours play themselves out. They recognize the intensity of these feelings and experiences but respond to them in a composite way i.e. they are unable to differentiate between behaviours that are a trauma consequence and behaviours that are part of normal adolescent development. Thus, the focus of counselling tends to be on issues like control, safety, and health. It ignores other important foci such as sexual trauma recovery, reclamation of affirmative sexuality and positive sense of personal acceptance. This lacuna could well be handled by orientation of staff to traumagenic dynamics, for example, how the same experience can give rise to diverse behavioural outcomes (increased sexual behaviours versus phobic avoidance of sexuality) depending on how the child has internalized the trauma.

Children from this background have a fragmented sense of attachment and affiliation. Every child likes to have a notion of the ideal and whole family. In the absence of this ideal, it is not surprising that intense yearning develops. In the light of the kind of neglect and trauma they face, it stands to logic that they should seek/ desire the presence of a protective male/ father figure. While this desire may have patriarchal underpinnings, it still has critical implications in the development of feelings of security. Thus, in any intervention, it would be important to create a reassurance about the long term commitment of the agency/ agency staff that in some ways meets the need described above.

#### f) Response to Emotional and Behaviour Issues

Some staff have never confronted or asked children about even serious behavioural issues such as in case of the child who wrote on the wall with her menstrual blood. Some staff said: 'We just leave it and see—certain behaviours may just disappear' and 'if we probe everything the relationship also goes.' Staff also fear that when they get involved in children's emotional concerns, they (children) get very intimate with the staff. Some children then say 'there is no life without you' and tend to attribute roles (often they are maternal roles) to the staff and insist on relating to them a certain way i.e. there are attachment and transference issues which the staff find difficult to deal with.

Staff responses to adolescent/ sexuality issues have included an attempt to 'create a family environment' and the girls are asked to address boys as 'anna' (brother) and the staff tell the girls to be like 'brothers and sisters'. However, staff acknowledge that there is a confusion created in the minds of the girls—between how they are told they should relate to the boys and how they feel.

No responses to helping children deal with sexual abuse and trauma issues were described, except in one instance, where agency staff spoke about a a girl rescued from trafficking who had a bag in which there were various objects that would belong to/ be used by men, such as handkerchiefs, watches etc. She would allow no one to touch the bag...until she finally brought out the objects one day and shared her story with one of the counsellors...each item in the bag was representative of a man who had been in contact with her and what he had done to her. No attempt was made to coerce her but they just waited a long time until she trusted them enough to tell about her life.

#### **Analysis**

What is striking here is an exclusive focus on the behaviour and not its context/ antecedents. Agency staff have not been trained in individual work with children to carry out behavioural analysis. Such an analysis helps in identifying the fundamental cause, consequent emotions and related thinking/ decision processes that ultimately culminate in the said problem behaviour. When a child feels acknowledged that the validity of the child's fundamental frustration/ resentment is acknowledged and respect is accorded to the emotional/ thinking processes, the receptivity of the child to further suggestions is that much more.

#### g) Addressing Medium to Long Term Issues

Agency staff were asked what measures were used, apart from or in addition to education, vocational training and job placement, to assist children's medium to long term concerns. In particular, given that abuse forms a major part of these children's life experiences, how are their abuse and trauma issues addressed in ways that avert negative impacts in the long term or in children's adult lives.

Staff grapple with children's long term concerns of 'I cannot have a settled life' (referring to marriage) and 'what is my future in a world where sexual abuse is not accepted?' One of the agencies said that there are certain districts known for prostitution and therefore no one wants to marry girls from that area. Similarly, devadasi children continue to suffer stigma and discrimination in later life as people refuse to marry them —in fact, some of the devadasi mothers tell the agency that 'you get boys to marry our girls, else we have to dedicate them...' meaning that the stigma and discrimination against devadasi children places them at risk of becoming devadasis. The agency claimed that its devadasi children were 'very strong and empowered'

They stated that children's knowledge and awareness of the Devadasi system and their consciousness now (after having been cared for at the institution), that it was a system of abuse and that their mothers had been abused had empowered them; however, they also said that this knowledge and awareness had made children feel vulnerable to stigma and discrimination. Thus, they were not able to articulate how empowerment was brought about.

One agency stated that they encourage children to 'disconnect the past from the future' by saying 'sexual abuse is one of many incidents that happened in your life, not the only one...you have had accidents, for instance, and scars if you hurt your foot but that won't get in your way...it is one incident. Like that, sexual abuse is one incident.' This is the strategy used to empower children who have undergone sexual abuse i.e. through inducing a strong future orientation.

One agency working with devadasi children also explained how initially the children's institution was in Bangalore but after a few years, it was moved to Koppal. The reason for this decision was that living in Bangalore, children were growing accustomed to city life, a far cry from their home circumstances and

#### Analysis

Child sexual abuse issues, whether within the family or outside (through trafficking, sex work and other means), if left unresolved, can have a range of medium to long term consequences for children. In the medium term, they could leave the child vulnerable to subsequent victimization, and to high risk sexual and other behaviours such as delinquency and substance abuse; in the long term, as she emerges into young and middle adulthood, she may suffer discomfort in forming and maintaining intimate relationships, marital problems, sexual dysfunctions and/or avoidance of or phobic reactions to sexual intimacy (due to flashbacks).

While it appears that agencies address longer term issues of community reintegration through education, vocational training and job placement, it is less clear how they address psychosocial issues from a medium to long term well-being perspective. First, addressing medium to longer term issues requires agency staff to have an understanding of the longer term impacts that child sexual abuse can have, and this understanding was not evident in the agencies' discussions.

Provision of physical care and opportunities of education and training are important but cannot make up the entire preparation package for medium-to longer term issues, and nor can they substitute for psychosocial care and assistance required by these children in order to address the trauma they experience. While it is certainly desirable to encourage a future orientation in the children's thinking, one that does not dwell too much on the past, there are some issues with the adoption of this strategy alone.

First, this is too simplistic a way of looking at abuse, and it indicates the lack of agency staff's understanding of the deep, long-standing impacts childhood traumas have on individuals. Second, it is hardly possible for individuals to 'disconnect' themselves from the past and be and do in the future in ways that are not influenced by their past. This does not mean that they do not move on from past (traumatic) events or cannot do differently in the future.

What it means is that it is necessary to enable children to examine and process the traumatic events in ways that ensure genuine healing and recovery. This will enable them to then feel stronger to meet expectations, aspirations and challenges in their future lives. If the trauma experience remains unprocessed, the concerns and uncertainties felt during the time of the

trauma or later, as a result of it, continue to exist, and this will not allow children to grow into adults who will negotiate any future trauma with resilience and effectiveness. Thus, as discussed earlier, there are immediate and long term impacts of trauma and abuse that require to be included in the medium to long term care plans for children affected by gender and sexuality vulnerabilities.

## h) Implications for Staff Training and Capacity Building

- Skills in emergency psychological responses to children who have gone abuse and trauma (such as in raid and rescue situations).
- Strategies for trust-building
- Skills in understanding perspectives and internal processing of children who have experienced sexual abuse/ trauma.
- Special skills and strategies for responding to difficult areas such as sexuality. This
  includes history-taking or eliciting trauma narratives as well as responding to related
  emotional and behavioural issues such as sexual acting-out behaviours versus normal
  sexuality development.
- Skills for conducting life-skills education, with emphasis on sexuality-related issues, also including identity formation and future planning.

## IV. Operational Challenges

#### 1. Delays due to Lengthy Bureaucratic Procedures

Obtaining permissions for various meetings and orientation programs was more time-consuming than anticipated. All systems have anywhere between three to five levels of official processing. For example, in the health system, to do a program for link workers, the paper work could involve sanctions from the Joint Commissioner, Chief Health Officer, Zonal Health Officer, Medical Health Officers, and PHC medical officers. Dispatch processes are often lengthy and delayed, and could go back and forth several times because of loss of letters/ files or absence of a signature or the absence of a specific order. Consequently, it took, on an average, nearly three months to obtain the requisite permissions to conduct the needs assessment and sensitization/ orientation workshops. Further, even when permissions were obtained, they were not transmitted on to the field staff (who finally needed to attend the workshops/ participate in the needs assessment processes) because this communication and instruction transmission itself entailed two or more levels of despatch process, which were frequently left undone or were relayed late, consequently adversely affecting information receipt and participation.

#### 2. Non-Government Organization Participation

Surprisingly, some of the permission-participation processes were not only problematic in the government departments but also in the NGO sector. Decision-making authorities in NGOs could take a personal decision on the need to attend such a program, based on whimsical personal reasons rather than professional ones (based on difficult experiences with an institution or its individuals, even if unrelated to this project); further, many times, no reason at all were provided for non-response or non-participation. Which cadre of staff to depute also became a matter of several rounds of discussion, thus delaying permission processes. Unlike the government, NGOs are not accountable to any nodal agency or body, thus each individual NGO has its own funding source and organizational structure and cannot be mandated to participate in an initiative such as this project.

#### 3. Lack of Recognition of Child Mental Health as a Priority

In a country where low socio-economic populations abound and the basic needs are barely met, mental health is not a priority and rightly so perhaps if we consider where mental health needs (self-actualization) feature in Maslow's hierarchy. In a context that is grappling with child mortality and malnutrition issues, child survival strategies are focussed largely on the 0 to 5 age group and the emphasis is on child health strategies such as nutrition and immunization. Consequently, child development, viewed from a mental health and disability framework has to jostle for its place in child health services and programs.

Adolescent health, as it is, is accorded lower priority even from a medical/physical health perspective. Adolescents actually have a place in sexual and reproductive health largely because the HIV pandemic propelled them into the spotlight of this domain; and although working on adolescent sexual and reproductive health involves many mental health aspects (such as life skills work), this is rarely recognized by health services and programs.

Child care institutions also reflect the idea that meeting children's physical needs, in terms of food, clothing, shelter, healthcare are of utmost importance and doing so is sufficient, or that mental and psychological well-being automatically follow from children's environments being modified i.e. difficult conditions at home to better living conditions and protection provided by institutions. Therefore, there is less effort to recognize child mental health needs and accord them priority in a response that aims to ensure children's over-all well-being.

Thus, in the experience of this project, in the light of the above issues, it has been hard to generate an interest in community child and adolescent mental health within various government departments and child care institutions as well as amongst child care service providers/ field workers, who perceive children's physical/ health needs to be not only paramount but sufficient in the meeting of child and adolescent development.

# 4. Limited Understanding of Preventive and Promotive versus Curative Child Mental Health

Given the general perception that (child and adolescent) mental health entails specialized care, usually available at tertiary healthcare facilities, the idea of incorporating child and adolescent mental health care at community level is difficult to inculcate in primary health care, child welfare and education systems. This is a challenge also because of the lack of understanding within systems and services of preventive and promotive mental health versus curative health, and of how mild problems if detected and addressed early on can prevent more severe problems from occurring. As a result, child mental health is perceived to include only illnesses and disorders; and these, in turn, are usually recognized and acknowledged when they become so severe that they render a given child dysfunctional and families' coping systems ineffective—which is when help is sought at a specialized/ tertiary healthcare service.

In other words, preventive and promotive interventions such as early stimulation and developmental activities need to be provided to all children in general and children at risk in particular (for example, pre-mature birth infants or orphan/ abandoned children) in order to ensure that their growth and developmental trajectories are age-appropriate and healthy i.e. so we promote the development of skills and abilities that most (normal) children have and prevent poor growth and disabilities/ problems in specific areas of child development. Similarly, for older children and adolescents, life skills' education is a preventive/ promotive child mental health intervention that aims at enabling them to acquire certain skills that they require for their day-to-day living in the present and future, thereby promoting skills in problem-solving, decision-making, conflict resolution and thereby preventing risk behaviours such as harmful sexual behaviour, substance abuse and conduct problems.

Preventive and promotive interventions are distinct from curative interventions that are provided to (a relative minority of) children. Curative interventions come into place, for example, when a child with severe anxiety refuses to go to school for weeks on end or a child with severe behaviour problems has a long history of physical aggression and has recently been suspended from school for causing injury to another child and necessitating medical attention. These examples certainly are of more serious nature. Curative interventions are also indicated in lower thresholds and disability. The distinction, however, is in the extent to which the child experiences personal distress or is unable to carry out role task performance or has crossed the parents' threshold of tolerance/concern.

In service providers, severe problems like dysregulated anger or disabling anxiety are perceived as 'aberrations' that can be handled by appropriate disciplining or friendly advice. The fact that these could be symptoms of a child psychiatric disorder is not well-recognized. Thus, the continuum of universal child mental health needs to children's concerns to one-off problems to established patterns of behaviour merge in a problematic way. Therefore, where preventive-promotive approaches can be applied for development and/or address mere concerns of children

or mild symptoms, the appropriate approaches are not used; neither are they used at the severe end of the continuum.

#### 5. Attitudinal Issues

A common trend amongst all service providers was resistance to examining the importance of this program. This was manifest in different ways. One was a tired resentment that there were so many designated tasks to complete, which were core to their job description and therefore, it would be difficult to accommodate this program (for example, the link workers said they have to conduct maternal and child health activities, data entry etc; the school teachers said that they had to contend with less staff strength, supervise distribution of uniform and related paraphernalia/ donations). The demands that the system places on them, therefore, does not allow them to see where and how they could accommodate child mental health needs. Another attitude discerned was one of averaging the significance of child mental health by saying 'sure, we do many other programs; we will do this also' implying a sort of desultory interest. In many sessions, the participants took the opportunity to vent their frustrations about the inadequacies and unfairness of the system that they work in, indicating that their general attitude is one of dissatisfaction. This substantially reduces enthusiasm to undertake any service delivery program. Overall, their attitude also indicated that these service providers do not place much importance of the mental health of children. This was obvious from the glaring gaps in their observations and common-sense understanding of children's emotions and behaviours particularly in difficult family/ community contexts.

#### 5. The Perception that Good Intention is Sufficient

One of the challenges in the staff skills and capacities assessment was getting them to recognize and acknowledge the gaps in the psychosocial care support/ services provided to the children they serve; and that these gaps arose from a lack of understanding of what child psychosocial care and support entails, due to the limited professional capacities and skills they possess. Most believed that 'dealing' with children in a way that was respectful and loving would prevent as well as address emotional and behaviour problems. While this might be true, such beliefs are only indicative of intent; they do not reflect knowledge of a child's problem, the context of a problem and methods to address the problem.

The challenge was to orient and sensitize them to the developmental needs of children and psychosocial processes through which many emotional and behaviour problems arise. This framework was not only missing, but there was also a tendency to trivialize its importance by this broad supercilious (and at times, sanctimonious) emphasis on their perception that their love and caring for children was not just undeniable but manifest in ways effective enough to deal with any problem children may have. This simplistic belief contradicts their unguarded moments of disclosure where they conceded that they are helpless when discipline cannot be maintained or in the face of difficult emotions, thus proving that their good intentions and caring attitudes are not a panacea for children's issues. However, despite repeated attempts and discussions on this score, they found it difficult to gain insight into their lack of systematic or methodology-based responses and the lack of skills thereof. This has implications for how future training and capacity building programs on child mental health will be received, and therefore indicates that a great many efforts will have to be made in order to increase their sensitivity to children's developmental needs and psychosocial factors that affect children's well-being, and to expose them to a larger repertoire of methods and responses.

## V. The Way Forward

The R.N. Moorthy Foundation project has generated enough experience and information to feed into the way forward. Towards this, the Dept. of Women and Child Development (DWCD), Government of Karnataka has already funded a three-year community child and adolescent mental health service project. Staff recruitments for this project have been made and community assessments i.e. discussions with parents/ caregiver/ children, which were pending, have been initiated. Given the bureaucratic structure in the permission processes and the inordinate amount of time that is lost to set up training programs, it has been decided that a designated person from the government funding agency will coordinate these processes.

The needs assessment with service providers revealed that most of them feel over-burdened by the already existing responsibilities allocated to them. Therefore, choosing a purely capacity building approach towards primary level care provision would have been a difficult proposition. Thus, appropriate consultation liaison models have been conceptualized to take the project forward. This final section of the report thus summarizes how the implementation phase of the project will proceed with the three sectors, health, education and welfare.

#### 1. Health: Primary Healthcare Centres

#### i) Objectives

- Increasing community awareness on child mental health issues.
- Early identification and referral of children with developmental disabilities and other emotional/ behaviour disorders.
- Provision of first level/ primary healthcare and services to children with developmental disabilities and emotional and behaviour problems, including parent and teacher guidance on home-based care and training for children with disability.

#### ii) Terms of Reference

The terms of reference for services and support provision to PHCs are as follows:

- NIMHANS project staff will maintain some community presence through/ along with link workers of the PHCs and conduct awareness/ education sessions (using health education materials developed for this purpose) for community/ caregivers along with link workers.
- NIMHANS will develop screening tools for use with children seeking other health assistance in the PHC i.e. so that MOs and ANMs can screen children who might be presenting for other medical complaints and thereby identify mental health issues also.
- NIMHANS team will provide services in PHCs (through periodic/ scheduled visits to PHCs) to children identified with behavioural/ emotional problems and developmental disabilities, through consultation liaison mode i.e. with intervention planning done by NIMHANS and executed/ followed up by PHC team.
- NIMHANS project team will help PHCs to re-vitalize the Sneha Clinics (focussing on adolescent health) through training and service provision.
- NIMHANS project will provide training and capacity building support to PHC staff through:
  - Training workshops/ classroom training on child mental health, with emphasis on practical skills (to enable PHC staff to provide first level responses to children with developmental disability and emotional/ behaviour problems).
  - On-the- job training and support PHC staff in the clinic and community, during awareness sessions/ home visits/ consultation liasions, working with them to demonstrate use of screening/ identification tools and first-level response.

#### iii) Outcomes

- Strengthening of knowledge/ skills/ capacities of PHC staff in child development and mental health service provision.
- Increased access to and availability of preventive, promotive and curative child and adolescent mental health services to children, ages 0 to 18, especially those living in difficult family and social situations.
- Development of training materials and manuals for use in District Mental Health Program, with the potential for replicability (state-wide and later country-wide).

#### 2. RBSK School Health Teams

#### i) Objectives

- Early and more accurate identification and referral of children with developmental disabilities and other emotional/ behaviour disorders.
- The extension of the school health teams' roles in the area of child mental health issues (including disability) in ways that enable them to provide first-level responses to children with emotional and behaviour problems, including parent and teacher guidance on homebased care and training for children with disability.

#### ii) Terms of Reference

The terms of reference for services and support provision to the RBSK school health teams are as follows:

- NIMHANS project will build on existing RBSK screening tools to develop more systematic/ in-depth screening tools for identification and referral of school children with developmental disability and emotional/ behaviour disorders.
- NIMHANS will provide support on setting up District Early Intervention Centres (DEIC), including recommendations on types of (low cost) aids/ materials.
- NIMHANS project will provide training and capacity building support to RBSK staff through:
  - Training workshops/ classroom training on child mental health, with emphasis on practical skills (to enable school health staff to provide first level responses to children with developmental disability and emotional/ behaviour problems).
  - On-the- job training and support to school health team by accompanying the school health teams on their visits to schools, and working with them to demonstrate use of screening/ identification tools and first-level response.
  - o Training of DEIC staff on early stimulation and other child development interventions, including use of aids/ materials.

## iii) Outcomes

- Strengthening of knowledge/ skills/ capacities of RBSK field teams in child development and mental health service provision.
- Increased access to and availability of preventive, promotive and curative child and adolescent mental health services to anganwadi/ school children, ages 0 to 6 and 6 to 18 respectively.
- Development of capacities and resources of DEICs enabling provision of more specialized care for children referred with developmental disabilities.
- Development of training materials and manuals for use in the RBSK program, with the potential for replicability (state-wide and later country-wide).

#### 3. Education: Government & Aided Schools

#### i) Objectives

- Increasing community awareness on child mental health issues.
- Early and more accurate identification and referral of children with developmental disabilities and other emotional/ behaviour disorders.
- Provision of first level/ primary healthcare and services to children with developmental disabilities and emotional and behaviour problems, including parent and teacher guidance on home-based care and training for children with disability.

#### ii) Terms of Reference

The terms of reference for services and support provision to PHCs are as follows:

- NIMHANS project will introduce on-the-job training component of the capacity building initiative. In this, project staff will visit each of the selected schools on a regular basis and assist school teachers with:
  - i) Classroom management strategies and creation of resource spaces (to the extent feasible).
  - ii) Identification and referral of children with developmental disabilities and acute emotional/ behavioural problems:
  - iii) Identification and management/ counselling of children with mild-to moderate levels of emotional/ behavioural problems (i.e. those not requiring referral).

<u>Note:</u> The school must commit to permitting some teachers to be part of the service/ assistance process along with the NIMHANS project team, in order that the concerned children may be receive continuous support and follow-up.

- At a later stage (6 months from now), NIMHANS project staff will identify interested teachers in each school and will provide training and capacity building through training workshops/ classroom training on child mental health, with emphasis on practical skills (to enable school teachers staff to provide first level responses to children with developmental disability and emotional/ behaviour problems).
- NIMHANS Project staff, in collaboration with teachers, will implement (and therefore demonstrate) life skill program packages with the children.

#### iii) Outcomes

- Strengthening of knowledge/ skills/ capacities of school teachers in child development and mental health service provision.
- Increased access to and availability of preventive, promotive and curative child and adolescent mental health services to school children, ages 6 to 18, especially those living in difficult family and social situations.
- Development of training materials and manuals for use in the Dept. of Education/ introducing school mental health programs, with the potential for replicability (state-wide and later country-wide).

## 4. Welfare: Anganwadis and CCIs

#### A. Anganwadis

#### i) Objectives

- Early identification and referral of children with developmental disabilities and other emotional/ behaviour disorders.
- Re-vitalizing the anganwadi space for promotion of child development.

#### ii) Terms of Reference

- In the immediate time i.e. in the next coming weeks, the project will begin by visiting selected anganwadis in Bangalore South Zone (the group of 45 anganwadi workers, for whom the orientation was conducted in the preliminary phase of the project) to develop a clearer understanding of field needs and realities as well as provide direct/ on-the job support and training to anganwadi workers i.e. working with Aws in their centres to demonstrate/ show them how to use screening tools etc.
- In the meanwhile, the project will, in collaboration with the DWCD staff (CDPOs and anganwadi supervisors), train anganwadi workers from anganwadis from selected areas for piloting the project i.e. in Bangalore South Zone. (This is also the group of 45 anganwadi workers, for whom the orientation was conducted in the preliminary phase of the project). Later, this training will be extended to other zones in Bangalore city.
- The project will proceed to developing child mental health materials in order to contribute
  to the standard anganwadi training program that is conducted by the JTC. In this regard,
  we will, with DWCD's support, collaborate with NIPCD and JTCs in incorporating child
  mental health content into existing initial and refresher training curriculums for anganwadi
  workers.

#### iii) Outcomes

- Strengthening of knowledge/ skills/ capacities of anganwadi workers in child development and mental health service provision.
- Increased access to and availability of preventive, promotive and curative child and adolescent mental health services to anganwadi children, ages 0 to 6 and 6 to 18 respectively.
- Early identification of (and referral for) disabilities.
- Development of training materials and manuals for use in anganwadis, with the potential for replicability (state-wide and later country-wide).
- Strengthening of child development/ disability/ mental health components in the JTC training program for anganwadi workers.

#### **B. Child Care Institutions (CCIs)**

#### i) Objectives

- Provision of effective first level response by care providers and continued protocol-based/ professional counselling for emotional and behavioural issues.
- Greater knowledge and skills amongst CCI staff of child development issues as well as special concerns such as neglect, abuse, trauma and sexuality.

#### ii) Terms of Reference

- The project team will develop training materials for each of the five categories of CCIs.
- Training will be provided to interested CCIs in their respective groups/ categories.

- The project will introduce on-the-job training component of the capacity building initiative by visiting the interested CCIs and assisting staff with children identified with emotional or behavioural issues. The project staff will guide CCI staff on the requisite interventions for each child identified by providing consultation. These interventions will be carried out by the CCI staff and periodically reviewed by the project staff. (Referrals to NIMHANS/ tertiary care facilities will be made when required).
- For particularly difficult or complex situations, a case conferencing approach will be used where other CCIs would also be invited to learn from the experience of how intervention plans are made.

#### iii) Outcomes

- Availability of specialized care to children in difficult circumstances, in keeping with their special needs and contexts.
- Acquisiton of new learning and skills, including use of creative/ counseling methods, by CCI staff.
- Increased knowledge and skills in CCI staff to address mental health needs (emotional and behavioural issues) of children in difficult circumstances, with special emphasis on loss/ grief/ trauma.
- Development of training manuals and materials for use in staff training as well as direct work with children.

## **Annexe 1: Selected PHCs and Catchment Areas**

	PHC/Area	Staff	No./Name of	Education Services in/ for Slum	
			Slums in PHC Catchment Area	No. of Anganwad is in Slums	No. of Government Schools serving Slums
1.	N.S. Palya	Medical Officer     health assistant     link workers	1 (G.D. Mara)	3	2 government Schools
2.	J.P.Nagar 1 <sup>st</sup> Phase	Medical Officer     health assistant     link workers	1 (Rajeshwari slum)	1	2 ( 1 primary & 1 high school)
3.	Avalahalli	1 Medical Officer 11 Health Assistants 3 Link Workers	3 (Avahalli slum, A.K. Colony Manjunatha Slum)	2	2 (1 Urdu school & 1 primary school)
4.	Kumaraswamy Layout	1 Medical Officer 1 Health Assistant 5 Link Workers	3 slums (Suludgudu slum, 15 E Bus Stop, 15 F Bus Stop)	3	3 (Kadrenhalli, 15 E, 15 F Bus Stops)
5.	Banashankri	Medical Officer     health Assistant     Link Workers	5 (Yarabnagar, Pragatipura, Hari Colony, Sarbandepalya)	9	4 (incl. 1 Urdu & 1 Tamil school)
6.	Tavrekere	Medical Officer     Health Assistant     Link Workers	3 (Bovi Colony, Guruappan Palya, Jogi Colony)	4	1 government school (Bovi Colony, Guruappan Palya)
7.	Adugodi Dispensary	Medical Officer     Health Assistant     link workers	4 (Jakasandhra, Madiwala, Jyothi Nivasa Mastri Palya)	5	3 (Koramangla Primary School, Mastri Palya Primary School,
8.	Adugodi	Medical Officer     Health Assistant     Ink workers	2 (Rajendranagar, Egipura)	3	Madiwala Primary School)
9.	Koramangala	Medical Officer     Health Assistant     Ink workers	2 (Indra Gandhi, Srini Wagilu)	2	2 (Srini Wagilu Lower Primary School, Ejipura Primary & Secondary School)
10.	Vidyapeeta	Medical Officer     Health Assistant     Link Workers	2 (Jamshaktinagar, Patanamma)	2	1 (in Jamshaktinagar)
11.	C.T. Bed	1 Medical Officer 1 Health Assistant 4 Link Workers	3 (Manjunatha Colony, A.K. Colony, Sanjaynagar)		No government schools; 1 aided school (Kamala Nehru School)
12.	Bapujinagar	1 Medical Officer 1 Health Assistant 8 Link Workers	4 (Shamanna Garden, Handi Gudslu, Chowdappa Layout, Hosauradahalli)	8	2 (Hosauradahalli School, Bapujinagar School)
13.	T.R. Mills	1 Medical Officer 2 Health Assistant 6 Link Workers	3 (Ambedkar, Boregowda, T.R.Shamannana gar)	2	1 (in Ambedkarnagar)

# Annex 2: ANMS and Link Workers from Selected PHCs

The following are the numbers of ANM/Link Workers who participated in the assessment and sensitization workshop:

PHC	No. of ANM/Link Worker
Avalhalli	5
J.P. Nagar	8
Banashankari	3
N.S. Palya	2
Taverekere	7
Kumaraswamy Layout	7
Yarabnagar	1
UFNC	2
Wilson Garden	1
Koramangala	4
Bapujinagar	1

# **Annex 3: RBSK School Health Teams**

The following are the RBSK school health teams (Bangalore Urban) who participated in the awareness and sensitization workshop:

Zone	Areas Covered	No. of RBSK Doctors
Anekal	Chandapura, Marsur, Attebele	3
East	K.R. Puram, Mahadevpur Constiuency	5
North	Yelahanka, North Taluk	5
South	Konankunte	1
South	BTM Layout, Jayanagar, Padmanabhnagar	6
South	Basvangudi, Vijayanagar, Chckpet	1

# Annexe 4: Selected Government and Aided Schools The following are the schools who participated in the assessment and sensitization workshop:

	School	Block
1	Government Upper Middle Primary School, Yarabnagar	1
2	Government Middle Primary School, Koramangala	3
3	Government Higher Primary School, N.S. Palya	3
4	Government Higher Primary School, Bapujinagar	2
5	Government Lower Primary School, Mestripalya	3
6	Government Higher Primary School KNPS	1
7	Government Higher Primary School Vnagar	1
8	Government Middle Primary School, Sarakki	1
9	Government Higher Primary School, K.S. Layout	1
10	Government Tamil Higher Primary School, Bhavaninagar	1
11	Government Higher Primary School	1
12	Government Higher Primary School, Egipura	3
13	Government Middle Primary School, Taverekere	3
14	Government Upper Primary School, K.S. Layout	1
15	Government Middle Primary School, Madiwala	3
16	Government High School, Sarakki	1
17	Government Higher Primary School, Veerabhadranagar	1
18	Government Higher Primary School, Kumaraswamy Layout	1
19	Kamala Nehru Aided School, C.T. Bed	1
20	Government Higher Primary School, Karisandra	1
21	Government Tamil Higher Primary School, Banashankari II Stage	1

# Annexe 5: Selected Anganwadis, Bangalore South Zone The following are the anganwadis that participated in the assessment and sensitization workshop:

	Anganwadi Location	PHC Area
1	Kumaraswamy Layout I	Kumaraswamy Layout
2	Kumaraswamy Layout II	Kumaraswamy Layout
3	Pragatipura	Yarabnagar
4	Hari Colony	Yarabnagar
5	Rajeshwarinagar Slum	J.P. Nagar 1 <sup>st</sup> Phase
6	Gangadharanagara	Yarabnagar
7	Vinobha Colony	Avalahalli
8	Cauverynagar	Banashankari
9	Pantharpalya	Avalahalli
10	Sriniwagilu Kendra	Koramangala
11	Indira Gandhi Slum, Ejipura	Koramangala
12	Jawaharlal Nehru Slum	Yarabnagar
13	Yarabnagar II	Yarabnagar
14	Bilal Masjid	Tavarekere
15	Guruappan Palya	Tavarekere
16	Bismillahnagar	Tavarekere
17	Tavrekere	Madiwala
18	Sarabande Palya I	Yarabnagar
19	Sarabande Palya II	Yarabnagar
20	Yarabnagar I	Yarabnagar
21	N.G. Palya	Tavarekere
22	N.S. Palya III	N.S. Palya
23	N.S. Palya I	N.S. Palya
24	M.G. Palya I	Singasandra
25	Someshwara Colony, N.S. Palya	Madiwala
26	New Madiwala	Madiwala
27	New Madiwala	Adugodi
28	Rajendranagar-1	Koramangala
29	Rajendranagar-2	Koramangala
30	Rajendranagar-3	Koramangala
31	Rajendranagar-4	Koramangala
32	Rajendranagar- 5	Koramangala
33	Rajendranagar- 6	Koramangala
34	Hale Madiwala III	Madiwala
35	Jyoti Nivasa Slum	Adugodi
36	Hoserihalli	Banashankari
37	Bhuvaneshwarinagar II	Banashankari
38	Itmadu	Banashankari
39	Mysore Road	Bapujinagara
40	Ananthanagara	Bapujinagara
42	Mysore Road	Bapujinagara
43	Shamannanagara	Bapujinagara
44	Shamannanagara	Bapujinagara
45	Shamannanagara	Bapujinagara
46	Jakkasandra, Sarjapura Road	Adugodi Dispendsary
_ +0	Jakkasanara, Jarjapura Kuau	/ raagour Disperiasary

# Annex 6 (a): Child Care Institutions Contacted

The table below presents a list of child care institutions which were contacted via e-mail, post and telephone, in order to invite them to participate in the needs assessment and sensitization workshops. It also shows the agencies/ numbers of responses received, in terms of in terms of response to phone calls/ e-mail and actual participation in the needs assessment processes.

Note: Some agencies were not reachable on the address/ contacts provided on the DWCD list of CCI; some responded when contacted but may not have participated in the needs assessment/ workshop because they no longer work with children/ children in a concerned area to unknown or for reasons not stated by the agency.

CCI (1):	Street & Working Children			
SI.No	Child Care Institution	Not reachable/ Non- Response	Responded through E-mail/ Phone	Participated in Needs Assessment Workshop
1	ECHO SPARSHA			✓
2	Paraspara Trust			✓
3	YMCA Dream Home			✓
4	Abilashrayam Trust		<b>✓</b>	-
5	VasudhaNele		<b>✓</b>	-
6	New Home		<b>✓</b>	-
7	Sathi Society		<b>✓</b>	-
8	ChinnaraTangudhama			✓
9	Precious Children Home		<b>✓</b>	-
10	Nest Project of FIDES India Society		<b>✓</b>	-
11	Agape Children Centre	✓		
12	BOSCO Yuvodaya			✓
13	AuxiliumNavajeevana			✓
14	The Association for Promoting Social Action (APSA)			<b>√</b>
15	Morning Star Learning Centre			✓
16	Bosco Mane			✓
17	MakkalaSahayavani			✓
18	BoscoVikas/ BoscoNivas			<b>√</b>
19	BoscoSumanahalli			<b>√</b>
20	Integrated Programme for Development of People (I.P.D.P) (Bangalore Forum for Street & Working Children)		✓	

	D=D0	✓		
21	REDS	· · · · · · · · · · · · · · · · · · ·		
22	Chaithanya	•		
23	Association of People with Disability		Ť	
	(A.P.D.)			
24	Vidyaranya Education and Development Society			✓
25	Vidyaranya Education and Development Society ®, Yelanka			✓
26	SnehaBharathi Education Society		✓	
27	Jeevan Public Trust		✓	
28	Trust		✓	
29	Outreach	<b>✓</b>		
	rphan and Abandoned Children			
SI. No	Child Care Institution	Not reachable/ Non- Response	Responded through E-mail/ Phone	Participated in Needs Assessment Workshop
30	Abilashrayam Trust		<b>✓</b>	
31	ShishuMandir Home			✓
32	St.Mary's Orphanage		✓	
33	Ashraya Children's Home			
34	SOS Children's Villages of India		✓	✓
35	St.Michael's Home	<b>✓</b>		
36	SumangaliSevaAshrama		✓	
37	Mathruchaya		✓	<b>√</b>
38	Vathsalya Charitable Trust	<b>✓</b>		
39	Kirubai Children's Home		<b>✓</b>	
40	JnanaMandira		<b>✓</b>	
41	NirmalaShishuBhavan			✓
42	'Balya' Free Home for Children		<b>√</b>	
43	Happy Home Orphanage Mission			✓
44	BalaYesuBhavan			<b>✓</b>
45	AnathaShishuNivasa		✓	

Children with Disability			
Child Care Institution	Not reachable/ Non- Response	Responded through E-mail/ Phone	Participated in Needs Assessment Workshop
JyothiSeva Home		✓	
Ashakirana School,	✓		
MathrushreeManovikasa Kendra	✓		
		✓	
			✓
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Ashaniketan		<b>V</b>	
Gerzim Boys Home	<u> </u>		<b>√</b>
Retarded Citizens			
Cheshire Homes, India		✓	
Samarthanam	✓		
Shree Ramana Maharishi	✓		
National Association for the Blind	✓		
IIV Infected/ Affected Children			
Child Care Institution	Not reachable/ Non- Response	Responded through E-mail/ Phone	Participated in Needs Assessment Workshop
Calvary (Home of Hope For Boys, Home of Hope For Girls, Home of Hope For Special Children			✓ ·
Infant Jesus Children Home			<b>✓</b>
Sneha Care Home and Shining Star School		<b>✓</b>	
Freedom Foundation			✓
Support			✓
	oilities		
Child Care Institution	Not reachable/ Non-	Responded through E-mail/ Phone	Participated in Needs Assessment Workshop
Makkala Jeevodava			√ ·
Visthar			<b>√</b>
	JyothiSeva Home Ashakirana School, MathrushreeManovikasa Kendra SWANTHANA NirmalaShishuBhavan AmbigaraCholdaiahEducation Glory Foundation Trust Missionary of Charity Akshara AthmaSakshi Sahana Humanitarian Hands Ashraya AshaNiketan Gerzim Boys Home Karnataka Parents Association for Mentally Retarded Citizens Cheshire Homes, India Samarthanam Shree Ramana Maharishi National Association for the Blind HIV Infected/ Affected Children Child Care Institution  Calvary (Home of Hope For Boys, Home of Hope For Girls, Home of Hope For Special Children Infant Jesus Children Home Sneha Care Home and Shining Star School Freedom Foundation Support Children affected by Gender/ Sexuality Vulnerak Child Care Institution  Makkala Jeevodaya	Child Care Institution	Child Care Institution

Note: All Bosco Institutions are under the same management and were therefore represented by 3 staff at the workshops.

Total No. of CCIs Contacted: 72

No. of CCIs who did not respond/ were not reachable: 14

No. of CCIs which Responded (but did not participate in Needs Assessment Workshops): 29

No. of CCIs participating in Needs Assessment Workshops: 29

# Annex 6 (b): Child Care Institutions Categorizations

The table below presents a revised categorization of child care institutions which responded and participated in the needs assessment workshops. (This revision to the original categorization was based on the more detailed information that was obtained from the CCIs during the assessment process).

Primary Focus of \	Work with	Children
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Secondary/ Associated Areas of Work with Children

	Child Care Institution	Street Working Children	&	Orphan and Abandoned Children	Children with Disability	HIV Infected/ Affected Children	Children with Gender/ Sexuality Vulnerabilities
1	ECHO SPARSHA						
2	Paraspara Trust						
3	YMCA Dream Home						
4	ChinnaraTangudhama						
5	BOSCO						
6	Auxilium Navajeevana						
7	The Association for Promoting Social Action (APSA)						
8	Morning Star Learning Centre						
9	Vidyaranya Education and Development Society						
10	ShishuMandir Home						
11	SOS Children's Villages of India						
12	Mathruchaya						
13	NirmalaShishuBhavan						
14	Happy Home Orphanage Mission (Karunalaya Trust)						
15	Bala Yesu Bhavan						
16	Glory Foundation Trust						
17	Karnataka Parents Association for Mentally Retarded Citizens						
18	Calvary Trust						
19	Infant Jesus Children Home						
20	Freedom Foundation						
21	Support (Sumanhalli)						
22	Makkala Jeevodaya						
23	Visthar						

# Annex 6 (c): Child Care Institutions' Services and Capacities

The table below presents a profile of child care institutions which responded and participated in the needs assessment workshops. (The details of their services and capacities is based on the information that was obtained from the CCIs during the assessment process).

CCI (1): Street and Working Children

Agency/ CCI	Target Popu				Service	Delivery			Activitie	S		No. of
	Type of Problems/ Children	Gender/ Age Range	Open Shelters	Institu- tional Care	Vocational Training (Incl. job placeme nt)	Identification of vulnerable children through Community/ Field Presence	Community Awareness/ Training/ Advocacy	Substance Abuse Awareness/ Treatment interventions	Response to Conduct Problems/ Juvenile Crime	Life Skills (incl. sexuality issues)	Response to Other Emotional / Behaviour Problems	Child Care Staff for Training
YMCA	Street/ abandoned/ runaway child; orphan & semi- orphan; beggars	Girls and Boys; 6 to 18 years	Х	Х	Х	Х		Х		Х		18
Navajeevana Auxilium		Girls only; 6 to 17 years		Х	Х	Х				Х		
Makkala Sahayavani		Girls and Boys		Helpl	ine Services							10
Vidya Ranya	Runaway children; children with drug abuse/ sexual abuse problem; trafficked children, sex workers' children, children of single parents	Girls and Boys	х		Х	Х	Х			Х		65
APSA	Children in conflict with law, abandoned/ abused children, HIV infected/ affected children, children with substance abuse	Girls and Boys; 8 to 18 years	Х	Х	Х	Х	Х			Х		28
Echo	Children in conflict with law, care & protection	Girls and boys, age 8 to 18		Х	Х		Х		Х			
Bosco	Street children,	Girls and		Х	Χ	Х	Х	X		Х		57

	child labourers, children in conflict with law, beggars	boys; age 5 to 22							
Paraspara	Child labourers	Girls and boys; age 7 to 18							
Chinnara Tangudhama Sparsha Trust	Street children, drop-out children, beggars/ rag pickers		X	X	Х	Х			27

CCI (2): Orphan and Abandoned Children

Agency/ CCI	Target Popula	tion		Types of S	ervices						
	Type of Problems/ Children	Gender/ Age Range	Institutionalized Care	Foster Care	Adoption	Community Awareness /Camps	Early Stimulation/ Developmental Activities	Addressing (Self) Identity Issues	Life Skills	Response to Emotional/ Behavioural Issues	No. of Child Care Staff for Training
Shishu Mandir	Economicaally Challenged background children, Single parent and Abandoned children	Girls & Boys 0-20yrs 20+ also	X			X			X		70
Bala Yesu Bhavan	Semi-Orphan, Poor Family, Broken Families	6-17yrs									?2
Shishu Mandira	Children in need of care & protection under JJA, Abandoned, Orphan, Relinquished, Physically/Sexually abused, Rescued from trafficking, Beggary, Broken & Neglected families, Missing, Run away, Mentally/Physically challenged etc	0-6Yrs	X		X	X (CWC and District Child Protection Unit)					17
SOS Villages of India	Parentless children	0-25yrs	X	Х		X			Х	Programmes	90
Mathruchaya	Cradle babies and Older children	0-6yrs	Х		Х	Х			Х		4
Karunalaya Trust	Orphan and semi- orphan	6-12yrs	X					_		community	6

# CCI (3): Children with Disability

Agency/ Target Population			Service Delivery					Activities				
CČI	Type of Problems/ Children	Gender/ Age Range	Institutiona li-zed Care	Day Care	Vocational Training	Parents' Groups/ Education	Community Awareness/ Advocacy	Develop- mental Play/ Early Stimulati on	Self- Care Skills Traini ng	Response to Emotional/ Behaviour Issues	Other Interventions (Speech/ Physiotherapy)	No. of Child Care Staff for Training
Vidyaranya (Spurthi Residential School for Mentally Challenged Children)	Mentally Challenged Children from the Urban and Rural Communities(with parents/ families)	6-18yrs	Х		X	Х	Х	X	X	Limited extent		39
KPAMRĆ	Mental Retardation and other Developmental disabilities in Children from Community (with parents/ families)	6-14yrs – day care (21yrs & above Residenti al care)	X	Х		Х	Х	X	Х	Х	Х	07
Glory foundation	Physical/ Intellectual Disability in Children from Community (with parents/ families)	9-20yrs	X						X			2
Nirmala Shishu Bhavan	Physical/ Intellectual Disability in Orphan/ Abandoned Children	1-14yrs	X					X	X			
Morning Star	Children with Severe/ profound disability (bed- ridden)		X					Х				5

# CCI (4): HIV Infected/ Affected Children

Agency/ CCI	Target Population		Service Delivery		Activities						
	Type of Problems/ Children	Gender/ Age Range	Institutional Care (incl. medical treatment)	Education	Community Awareness/ Training Advocacy	Early Stimulation/ Developmental Activities	Education about Illness	Disclosure about Illness	Loss/ Grief/ Death Work	Community Integration	No. of Child Care Staff for Training
Sumanahalli	HIV/AIDS, leprosy, disability, abused/ disabled adolescent girls	4-16yrs	Residential care, education, health, Rehabilitation	X (own school)	X		X				36
Calvary Chapel Trust	HIV infected/ affected children, orphan/ abandoned	3days to 22yrs	X	X	X		X		Limited (Death)	X	
Deena Seva Charitable Trust (Infant Jesus Charitable Home)	HIV infected/ affected children, orphan/ abandoned	0-18yrs	X	X			X		Limited (Death)		18
Freedom Foundation	Children infected/affected by HIV	6-20yrs 4-21yrs children)		Х	Support to HIV affected/ infected children in community					X	06

CCI (5): Children Affected by Gender & Sexuality Issues

Agency/ CCI	Target Population			Services			No. of			
	Type of Problems/ Children	Gender/ Age Range	Raid & Rescue	Identification of vulnerable children through Community/ Field Presence	Institutional Care	Healing Interventions for Trauma/ Abuse	Response to Emotional/ Behaviour Issues	Life Skills Education	Reintegrati on into Communit y(Long Term Plans)	Child Care Staff for Training
Visthar	Girl children from Devadasi community	6-16yrs		X	Х			Х	Х	11
Makkala Jeevodaya	Run away from home, sexually abused and destitute	3-16yrs			X			X		10
Vidyaranya Rainbow Program	Trafficked girls/ Girls living in difficult/abusive family circumstances		X	X	X			X	X	
APSA	Street children/ trafficked girls/ girls living in difficult/ abusive family circumstances		X	X	Х			Х	X	
Navajeevana Auxilium	Street children/ trafficked girls/ Girls living in difficult/abusive family circumstances			X	Х					

<sup>\*</sup>Where there appears to be information missing i.e. in terms of staff numbers or children's age groups, please note that this information is to be updated when made available by the concerned agency.

# Annex 6 (d): CCI Workshop Content and Guidelines

# CCI (1): Street & Working Children

- 1. List the needs/ vulnerabilities of your target groups. Categorize them into groups such as: family relocation, job placements, health needs, providing temporary shelter, negotiation on behalf of the street child, advocacy.
- 2. Initial Contact
- a) How do you establish first contact with a child?
- b) How and in which spaces do you go about getting to know and understand these children?
- c) How do you assess their basic needs and the challenges of street life?
- d) What interventions do you carry out to help them adjust and plan for a healthier future?
- \*List issues and methods used in each case. Provide examples/ stories where possible.
- \*Discussion: What areas do you need more support/ training in?
- 3. Assessing and Addressing Problem Situations
- a) What problematic/ traumatic situations do these children face?
- b) What are some of their worrying behaviours?
- c) What techniques do you use to engage them in an effective counselling relationship?
- d) What are the interventions that you use to address problem situations/ behaviours?
- \*Discussion: What areas do you need more support/ training in?
- 4. Long Term Processes
- a) What special issues related to adolescence do you face?
- b) How do you address complex areas like sexuality?
- c) What type of long-term plans do you make for these children?
- d) How do you ensure implementation and receptivity to these plans?
- \*Discussion: What areas do you need more support/ training in?

## CCI (2): Orphan-Abandoned Children

## 1. Context of Contact with Orphan/Abandoned Children

- How do they come in contact with orphan-abandoned children?
- What age group of children? Sex/gender?

#### 2. Immediate Issues and Concerns

- What do they see as some of the immediate issues?
- What are first level responses and interventions to these issues?
- What kind of procedures and placements take place thereafter? (informing CWC, paperwork?)

## 3. Establishing Rapport and Relationship

- How do they build rapport with the child/ conduct initial enquiry/assessment? (methods of rapport building and inquiry)
- How do they build deeper understanding of a child's emotional/ behavioural issues? (methods used?)

#### 4. Emotional and Behavioural Issues

- What are some of the critical emotional and behavioural issues these children have? (according to age groups: under 5s, 6 to 12 and 13+)
- How are these handled?

#### 5. Medium-Long Term Issues

• What finally happens to the child?—in terms of placement, needs, addressing of problem issues, long term stability and well-being.

<sup>\*</sup>List issues and methods used in each case. Provide examples/ stories where possible.

<sup>\*</sup>Discussion: What areas do you need more support/ training in?

<sup>\*</sup>List issues and methods used in each case. Provide examples/ stories where possible.

<sup>\*</sup>Discussion: What areas do you need more support/ training in?

<sup>\*</sup>List issues and methods used in each case. Provide examples/ stories where possible.

<sup>\*</sup>Discussion: What areas do you need more support/ training in?

<sup>\*</sup>List issues and methods used in each case. Provide examples/ stories where possible.

<sup>\*</sup>Discussion: What areas do you need more support/ training in?

## CCI (3): Children with Disability

#### 1. Assessment and Identification

- How do you identify the type and severity of disability in children? (assessment format/ screening protocol?)
- Who are your referral sources and contacts? (where do you get them from/ who do you send them to?)

#### 2. Associated Emotional and Behaviour Problems

- How do you assess/ identify associated emotional problems? What are they?
- How do you respond to co-morbidity? i.e. associated behaviour or psychiatric problems?

## 3. Availability of Resources

- Does your set-up have in-house facilities for training and stimulation? (What types of facilities? Equipment? Trained Resource Teachers?)
- Or do children have to be sent out? (Where? To whom?)

## 4. Disability-Focussed Interventions

Is there an IEP—individual education program—protocol? (Describe it).

For younger disabled children, what type of early stimulation and education interventions do you provide?

For older children, what types of vocational, pre-vocational, life skills, relationship skills, sexual health programs/ interventions do you provide?

# 5. Safety Risks

- What do you feel are the risks for physical and sexual abuse of disabled children?
- What preventive interventions do you carry out?

## 6. Parent and Caregiver Support

 Do you have programs for parent/caregiver support/ education? Describe them...type/ content.

## **Mainstreaming and Advocacy**

- What strategic partnerships do you have for mainstreaming? Name and describe the type of strategy.
- Describe your advocacy initiatives.

## CCI (4): HIV Infected and Affected Children

## 1. Context of Contact with Orphan/Abandoned Children

- How do they come in contact with HIV infected and affected children?
- What age group of children? Sex/gender?
- What are the roots/ contexts (home, family...) that these children come from? What are the causes placing the child in a situation of vulnerability?

#### 2. Immediate Issues and Concerns

- · What are the immediate physical/ medical impact on the child?
- Are there recommended protocols that are followed (NACO, ICTC approaches)?

#### 3. Emotional and Behavioural Issues

- What is the developmental impact of the illness?
- What are some of the critical emotional and behavioural issues affected and infected children have? (according to age groups: under 5s, 6 to 12 and 13+)
- How are these handled?
- How do they respond to/ help the child deal with issues of loss/grief/death? (methods?)

#### 3. Illness and Disclosure Issues

- What methods/ ways do they use to explain the illness to the child—if child has it and if someone known/related to child has it. (young children versus older children).
- What methods/ ways do they use to disclose sero-positive status to the child? (young children versus older children).
- How do they handle the consequences of the disclosure?

#### 5. Other Issues

- How is ART enabled?
- What do they do with regard to the child's social integration? (dealing with stigma discrimination issues)
- How do they enable the child to deal with long-term issues like mortality?

<sup>\*</sup>List issues and methods used in each case. Provide examples/ stories where possible.

<sup>\*</sup>Discussion: What areas do you need more support/ training in?

<sup>\*</sup>List issues and methods used in each case. Provide examples/ stories where possible.

<sup>\*</sup>Discussion: What areas do you need more support/ training in?

<sup>\*</sup>List issues and methods used in each case. Provide examples/ stories where possible.

<sup>\*</sup>Discussion: What areas do you need more support/ training in?

<sup>\*</sup>List issues and methods used in each case. Provide examples/ stories where possible.

<sup>\*</sup>Discussion: What areas do you need more support/ training in?

## CCI (5): Children affected by Gender & Sexuality Vulnerabilities

#### 1. Context of Contact with Children

- How do they come in contact with affected children?
- What age group of children? Sex/gender?
- What are the roots/ contexts (home, family...) that these children come from? What are the causes placing the child in a situation of vulnerability?

#### 2. Immediate Issues and Concerns

- What do they see as some of the immediate issues?
- What are first level responses and interventions to these issues?

## 3. Establishing Rapport, Relationship and Narratives

- How do they build rapport with the child/ conduct initial enquiry/assessment? (methods of rapport building and inquiry)
- How do they build deeper understanding of a child's experiences/ issues and problems? How do you elicit a narrative? (methods used?)

#### 4. Emotional and Behavioural Issues

- What are some of the critical emotional and behavioural issues these children have?
   (according to age groups: 6 to 12 and 13+)
- How are these handled?
- What are some of the healing interventions used? (abuse/ trauma-focussed interventions)

# 5. Medium-Long Term Issues

- Knowing that abuse and trauma have long term consequences, what is done to minimize long term impact? (strategies/ methods/ interventions...)
- Raid-rescue-rehabilitation-repatriation- reintegration-redressal processes

<sup>\*</sup>List issues and methods used in each case. Provide examples/ stories where possible.

<sup>\*</sup>Discussion: What areas do you need more support/ training in?

<sup>\*</sup>List issues and methods used in each case. Provide examples/ stories where possible.

<sup>\*</sup>Discussion: What areas do you need more support/ training in?

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