Community Child & Adolescent Mental Health Service Project

7th Quarterly Report
April – June 2016

Dept. of Child & Adolescent Psychiatry, NIMHANS

Supported by Dept. of Women & Child Development,
Government of Karnataka

A. Project Objectives

With a view to addressing child and adolescent mental health service needs and gaps, the project aims to extend child and adolescent mental health service coverage, particularly to cover those who are most vulnerable. Project implementation entails 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, anganwadis and health workers. The specific objectives of the project include:

> i) Establishment of community-based child and adolescent services;
> ii) Training and capacity building of childcare workers and staff from various governmental and non-governmental agencies, including schools;
> iii) Draw from implementation experiences to develop a comprehensive community child and adolescent mental health service model that may be replicated elsewhere in the country.

B. Project Implementation: Activities and Progress

Given that much of this quarterly period was summer holidays, schools and child care institutions were closed. The Project therefore focussed on material development (in preparation for successive phases of Life Skills work and other interventions for children) as well as initiating work with cancer-affected children in Kidwai Hospital. A detailed account of the Project's preliminary work in Kidwai, an assessment of cancer-affected children's needs is included in this quarterly report. When schools re-opened in June, the Project resumed its remedial education program in government schools and reconnected with child care institutions to continue individual and group interventions there.

In all, during this quarterly period from April to June 2016, the Project reached out to 215 children, through individual or group services and 126 child care service providers/ professionals/ through training programs and other awareness/ orientation initiatives.

1. Mental Health Services in Schools

During the quarterly, school mental health work focussed on the remedial education initiative that the Project is in the process of piloting. More teacher workshops and demonstration of classroom-based remedial education techniques were initiated in the selected government schools.

### 1.2. Remedial Education Services in Government Schools

<u>a) 2nd Round of Teacher Workshops:</u>

In Continuation of the Workshops for Teachers, and following the orientation workshops on learning problems, the Project initiated the second round of teacher workshops as soon as schools re-opened in June. This round of workshops focussed on Neurological Processes in Learning.

Objective of Workshop: For teachers to analyze the best teaching-learning practices with an understanding of learning as a neurological process.

Process:
The teachers along with the HM of the school were present. The facilitator introduced herself and asked the teachers to introduce themselves. A rapport was built with the teachers. They were asked to recall a few things from the first workshop and the activities that followed it. The teachers were told that teaching should be based on the process of learning. They were asked to think about the time when they were really small and now when they are all working and asked if there have been any changes, to which they respond that there have been many changes. They expressed that they have learnt a lot based on their experiences. The facilitator explained to them that the brain is constantly learning and changing, it has the ability to change throughout life. This process is called as Neuroplasticity or brain plasticity. The facilitator drew a simple diagram of neuron on the board and explained the functions of each part of the neuron.
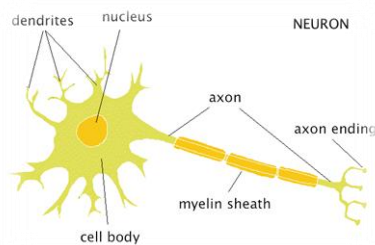
The facilitator explained that neurons have thread like structures called dendrites and when the dendrites of 2 neurons meet it is called as synapse. During learning messages are transferred through neurons. Information comes through dendrites, is processed in neuron and goes out through an axon. Research shows that as learning increases repeatedly the myelin sheath on the axon becomes bigger, thicker and stronger. Only when learning becomes repeated the myelin becomes stronger. The facilitator explained to the teachers that their primary duty is to create strong synapse which in turn would lead to stronger myelin sheath.

The next topic that the facilitator discussed was about how the brain learns. The facilitator told the teachers that when a baby is born it cries out loud because its lungs expand and it breathes. It cries for something else and every time it cries someone picks it up. This information is picked up by the brain and the synapses are formed. Through this the child learns that if it cries the mother or anyone else will pick it up. The facilitator explained that the teachers should create a bridge between previous year's syllabus and the present year's syllabus. It builds on previous knowledge. The facilitator shared with the teachers that only when the learning is repeated and when there are enough practice the myelin sheath becomes stronger and which in turn leads to a stronger memory.

The facilitator then moved on to neural fatigue and explained to the teachers that when the brain is learning neurons become tired after 3-5 minutes. After this short time the brain stops learning and the children don't learn anything. The facilitator explained this further with an example. She told that when the social studies teacher is teaching about Mughals and she teaches it for 40 minutes, the students would have stopped learning after sometime. She told the teachers that they could plan the lesson in such a way that for 10 minutes she gave factual information and for the next few minutes she could discuss about the personal details

of the king or the attire that people wore during that time. When the brain feels that it is new information it becomes active and starts learning again. The facilitator explained to the teachers that practice is how the brain learns but that should not hinder the learning. The facilitator explained that the teachers could teach one whole topic but they would have to make it interesting for the children to learn.

The facilitator explained to the teachers that the children can be told to read different topics from different subjects every 10 minutes at home. In the class the teachers should use activities to avoid neural fatigue.

The facilitator then moved on to explaining the limitations of working memory. The facilitator told the teachers that they won't be able to remember information about the first few lines with which this workshop was started. Similarly children also would have difficulties in remembering or recollecting information from the class on the previous day. The facilitator explained to the teachers that only if the information they have taught children is repeated in different forms children would be able to remember it better. The facilitator also gave an example of how this could be done in English class, she told the teachers that if they had taught nouns on the previous day and they were doing a literature lesson next day the teachers could tell the children to recognize the nouns in the text, this activity could be done for few minutes and the teacher could then carry on with the lesson. This way a link has to be created between two topics.

The facilitator explained to the teachers that along with neural fatigues, limits of working memory there are 2 other factors that stop the brain from learning and they were social life and stress/fear. The facilitator then explained to the teachers that a lot of children have difficulties at home; no proper food, alcoholic father who might be abusive, no proper sleep and many more which definitely affects the learning process. The facilitator told the teachers that they should always know the background of the children they are teaching and help children according to it. If a child who has an alcoholic father who beats him at night sleeps in the class, then there is no point in waking him up. If he is woken up then he would not be able to learn anything in the present class, instead if he let to sleep he would at least learn in other classes. The facilitator told the teachers that they should always understand the context in which the child is showing a particular behaviour. The facilitator asked the teachers if it would be fare to give a lot of home work to children who come from difficult families or backgrounds. She told the teachers that for such children they should give home works that the children themselves can do without any help or no home work at all.

The facilitator explained to the teachers that one of the biggest reasons why children don't learn is stress and fear. She told them that stress and fear affect our hormones and blood circulation. There are two reactions to stress and fear, the first one being flight: when the brain experiences stress it goes into flight mode meaning the body is ready to run away from the situation, blood rushes into extremities of leg and hand preparing the body to run. The second reaction being fight meaning when the body experiences stress it prepares itself to fight against what it senses as danger. The facilitator explained that when the child is scared because of the stick in teachers hand, the brain of the child switches to flight mode and it will do whatever it can to survive the situation but won't be learning. The facilitator told the teachers that when they stand next to the child yelling at them, the children don't learn, they might write what is required but that is out of fear and in fear children won't learn. During stress the 'CARTISOL' hormone is released which dries out the dendrites and no messages can be passed through it, which means no synapses are formed and hence no learning. The

facilitator told the teachers that they have to keep in mind all this before giving home work or before teaching a lesson.

The facilitator then told the teachers to plan a lesson from their subject based on their learning from the workshop. She told them that they should carefully keep in mind all the points they learnt and plan the lesson in such a way that the children are kept interested and there is no neural fatigue.

Table 1 (a): Orientation Workshops on Children's Learning Problems, April-June 2016

Name of School	No. of Teachers Reached
Government Kannada Higher Primary School.	7
Arundhatinagar Urdu School.	6
Total	13

Observations and Discussions:

School 1:

The session involved a lot of conversations and discussions. Demonstration of fear in children was done by the facilitator. The teachers related to how the children react in class when they hit or scold them. As and when the facilitator was explaining the learning process and the circumstances from which the children came from the teachers started applying this information to analyze their own methods. For example: the facilitator posed a dilemma about children who sleep in the class. She asked if they should be allowed to sleep. If they are woken up, they won't learn anything and the sleepy mood will continue throughout the other classes. This needs to be taken as an input by the teacher and the teacher needs to find out why the child feels sleepy. A few teachers related to this and shared their experiences.

The Head Mistress related the workshop to the teachings of one of the Prophets. She expressed that like the facilitator had told the teachers that if they get angry they should never shout at the children, they should walk out or drink water even the prophet has preached the same that the teachers should never scold or yell at children, if the teacher gets angry he instead should sit down drink water and calms himself or herself. The prophet also has preached that children never should be beaten they should always be spoken to with love. The head Mistress was very happy that what she learnt in the session is very similar to what the Prophet has preached.

The teachers decided that they will give easy home works to children that they can complete on their own and if they know that the child comes from a difficult background they will make the boy or girl sit in the class and do the home work.

Followed by this was a discussion on stress and fear. As this was going on a child walked in to give a book to the teacher. The facilitator stopped the boy and talked to him and asked what he learnt today in the class. The boy was startled and went silent. He was unable to say anything more than his name and class. When his subject teacher asked him what was taught in the class he was able to tell everything. Keeping this as an example the facilitator explained to the teacher that since she is a stranger the boy was scared and his mind automatically went into flight mode (fight and flight reaction was explained to them earlier) hence he was unable to say anything. But when his teacher whom he is familiar with asked, he felt safe and told everything. With this example the teachers were able to understand the concepts even better. The teachers were given an activity where they had to plan one lesson

based on this discussion. The methods had to be used based on their learning from the workshop. The facilitator requested the teachers to experiment with their own learning abilities by learning something entirely new in the next few months.

The Head Mistress was very cooperative and enthusiastic. She had made sure that all the teachers attended the workshop. The teachers were also very interested to learn. They were immediately relating to their methods of teaching and how they could better or rectify them. They requested us to come back and do more workshops which would help them teach better.

School 2:

The teachers and the Head Mistress decided to sit in the class along with the students as they had to be monitored. The Facilitator introduced herself to the teachers and the teachers introduced themselves. Since the children were present in the class it was more interesting. All of a sudden the facilitator pointed at a student and asked her to stand and started shouting at her, the child was very scared and could be seen trembling. Then the teachers related to how the students feel when they yell at them. The facilitator then called out another child and stood next to her and told her to write something. The child was unable to write, but when the yelling got harsher she scribbled something which was wrong. This showed that when teachers pressurize in this way children are not be able to learn as they are scared and their mind is in flight mode. Even if they write the right thing they will not be learning it as they are scared. When they are scared the blood rushes to the extremities and they are not able to concentrate. They might do what you tell them because they want to escape from the situation.

The facilitator requested the teachers to keep in mind that the students come from difficult backgrounds and explained that even if they are in class they might be preoccupied with their home situations. Considering all this the home work given to them should be what they feel confident doing on their own. A few teachers related that a few children had expressed to them that they are generally sleepy in the class because they do not get enough sleep at home due to different kinds of tensions. The teachers analyzed and discussed where the changes can be made in their teaching approaches.

The teachers were given an activity where they had to plan one lesson based on learning from the workshop. The methods used should be based on the learning from the (2nd level) workshop.

The Head Mistress was very keen to learn and so were the other teachers. As much as having the session in the class full of children was helpful it also led to a little disturbance and distractions for the teachers. A few teachers were able to relate to their methods of teaching and if they had to rectify it or better it. One teacher was not cooperative, he did not want to attend the session and he did not let another teacher also attend the session. One teacher constantly disturbed the session as it was going on.

b) Classroom Demonstration of word Activities

In conjunction with the workshops which were used to explain theory and concept to teachers, the Project team demonstrated classroom remediation techniques to teachers with their students. The objectives of these activities are:

- To help the children improve their vocabulary.
- To reduce and eradicate fear of learning in children.
- To reduce and eradicate fear of teachers in children.

The Method used was a series of (word) games. The basic instructions (for all games) for the children were:

To close all the books in front of them; each child should participate and listen carefully to the teacher as they play a game; the instructions of the activity are given to the children before the activity begins.

The basic instructions (for all games) for the teachers were: Not to reject any word; if the word given by the child is incorrect, the teacher must write it on the board and show the child why it cannot be accepted for this activity and/or the teacher can say it is a good word, but it cannot be taken for this activity as the mentioned alphabet is not present in the word; the teacher must ensure that students answer individually and every student gets a turn over a period of time; The students must not be told to write and learn these words.

At the end of the activity the facilitator spoke to the teachers, showed them the handout that documents the activities and once again explained the activities to her. She also explained that the vocabulary of children would improve on doing these activities everyday for just 5 minutes and it would help the teacher recognize and help students who might have trouble in reading or processing.

Table 1 (b) Classroom Demonstration of Remedial Education April-- June 2016

Name of the school	Activity	No of students reached.	No of teachers reached.
Arundhatinagar Urdu school.	Activity 1 and 2	24	1
Chamrajpet Kannada Higher Primary School.	Activity 3	26	2

Activity 1: Make a word
- The teacher asks the students to keep the books away.
- The teacher announces that they will play a word game for 5 minutes.
- The teacher draws a circle on the board.
- She asks the children to choose any alphabet from A-Z, she writes that alphabet in the circle.
- The teacher asks the students to name the words that contain the alphabet at either the beginning, middle or the end, anywhere in the word.
- As the students name the words, the teacher writes them on the board.
- After writing the word, the teacher reads the word out.

Notes:
- The teacher is instructed not to reject any word. If the word given by the child is incorrect, the teacher must write it on the board and show the child why it cannot be accepted for this activity. The teacher can say it is a good word, but it cannot be taken for this activity as the mentioned alphabet is not present in the word.
- The teacher must ensure that students answer individually and every student gets a turn over a period of time.
- The students must not be told to write and learn these words.

Activity 2: Make a word Using 2 letters

- The teacher asks the children to keep their books away.
- The teacher announces that they will play a word game for 5 minutes.
- The teacher draws 2 circles on the board.
- In one circle she writes a vowel. (a,e,i,o,u).
- In another circle she asks the students to choose any consonant and writes in it.
- The teacher now asks the students to make words using these alphabets.
- As the students name the word, the teacher writes it on the board and reads them.

Notes:
- The teacher is instructed not to reject any word. If the word given by the child is incorrect, the teacher must write it on the board and show the child why it cannot be accepted for this activity. The teacher can say it is a good word, but it cannot be taken for this activity as the mentioned alphabet is not present in the word.
- The teacher must ensure that students answer individually and every student gets a turn over a period of time.
- The students must not be told to write and learn these words.

Activity 3: Make as many words as you can
- The teacher asks the children to keep their books away and announces that they will play a word game for 5 minutes.
- The teacher asks the children to keep the paper and the pencil ready.
- The teacher writes a set of 7 alphabets on the board comprising any 2 vowels and any 5 consonants. (a,I,s,r,v,p,k).
- The teacher asks the children to combine any number of letters to make a word. Any alphabet mentioned can be used as many number of times and in any order to make a meaningful word.
- As the children name the words the teacher writes it on the board and reads it aloud.

 Notes:
- There could be many variations to this activity.
- The teacher could divide the class into 2 groups.
- As the child names the word the teacher must confirm the spelling of each word.
- In case a child reads the wrong spelling then the teacher writes it on the board and below it writes the correct spelling.
- The teacher must not comment about any such mistake or scold the child.

Observations & Discussions:
Activity 1:
The students were very responsive. They were able to give words that had the particular alphabet in them. Few children were not able to give the words that had the required alphabet. Those words were written on the board but also explained to the child that it cannot be taken for this activity as it does not have the alphabet. One child named a word that had another alphabet and when asked if it is the same alphabet as written on the board, the child said it is. This activity gave us an idea about each child's processing abilities.

Activity 2:

The children responded well. They gave many words that had the chosen alphabets. Few children could give words that had either of the alphabets, but after writing the word and showing that only one alphabet is present the children were able to rectify and come up with the words that had both the alphabets. A few children came up with words that had the sound of the alphabet but not the alphabet (alphabet a and f were chosen. The child gave the word enough, which has neither of these alphabets, but when read out it has the sound of the alphabets chosen).This activity helped the teachers know which child in the class might have issues in processing who might be good at it.

Activity 3:
The children responded well. A few children were able to come up with meaningful words. Most of the children followed the instructions well. Few children gave words that had either one or two alphabets but not all of it. It was explained to them as to why the word cannot be taken in this activity. The teachers felt it would be difficult to do this activity for them in all the classes as there was only 2 teaching staff. The teacher also mentioned that she had done the previous two activities in Kannada for the students and it was helpful. This activity made the children to think and come up with combination of words which had these letters.

2. Services in Child Care Agencies

2.1. Interventions in Children's Agencies for Care and Protection

a) Individual Services:
During this quarterly, the project provided individual services only in Government Boys home as all the children in other child care institutions had gone home for the vacation from April-June 2016. A total of 13 children were provided with detailed assessments and first-level inputs including referral to tertiary care facilities/ NIMHANS as required. Amongst these children, 32 child psychiatric problems were identified, 3 (9%) of which were emotional problems or internalizing disorders and 21(65%) were behaviour problems or externalizing disorders (refer table 2 (b)**)**. Despite this categorization (which is more for convenience), for children in institutions, most behaviour problems actually have a strong emotional basis, also related to their difficult and traumatic experiences in the home/family context. Most of the children seen in the Govt. Boy's Home were children hailing from low socio economic background and difficult homes. Out of these children with ADHD and runaway behaviour were the highest.

All the children in the institution have vulnerabilities due to psychosocial events that have led to poor emotional regulation mechanisms, of which difficult behaviours are a consequence. These psychosocial contexts are important in order to understand the child's experience while treating the psychiatric problems of all children. Hence, in addition to assessing and addressing the psychiatric problems of children, the project is also addressing the psychosocial contexts in which these problems occur. This is especially critical in institutionalized children who come from difficult circumstances. Table 2(c) shows the psychosocial contexts of institutionalized children's emotional and behaviour problems.

Table 2 (a): Total No. of (New) Consultations Disaggregated by Age & Sex, in Children's Institutions for Care and Protection April- June 2016

Age Groups	April		May		June		No. of Children
	Male	Female	Male	Female	Male	Female	
5 to 12 yrs	0	0	2	0	4	0	6
13 to 17 yrs	3	0	2	0	2	0	7
Total	**3**	**0**	**4**	**0**	**6**	**0**	**13**

Table 2(b): Child & Adolescent Disorders Identified in Children's Institutions in Care and Protection, April- June 2016

Problems/ Disorders		No of Issues Identified			
		April	May	June	Total
Emotional Problems	Other Anxiety Issues (incl. separation anxiety)	1	0	2	**3**
Sub-Total		1	0	2	**3**
Behavioural Problems	Conduct Symptoms : Anger/Aggression	1	1	2	**4**
	Conduct Disorder – Lying and stealing	1	1	2	**4**
	Runway Behaviour	2	1	2	**5**
	Substance abuse	1	0	2	**3**
	Attention Deficit Hyperactivity Disorder	0	2	3	**5**
Sub-Total		5	5	11	**21**
Learning disability	SLD	0	1	0	**1**
	Other learning issues	1	0	1	**2**
Sub-Total		1	1	1	**3**
Other Issues, incl. serious mental health issues and life skills issues	Life Skill Issues(sexuality, bullying etc)	1	1	2	**4**
	Physical disability	0	0	1	**1**
Sub-Total		1	1	3	**5**
Total		**8**	**7**	**17**	**32**

Table 2 (c): Psychosocial Contexts of Emotional/ Behavioural Disorders, April-June 2016

Psychosocial Context	April	May	June	No. of Contexts
Single Parents/Abandoned	1	2	1	4
Marital Conflict/Domestic Violence	1	1	3	5
Rescued from Trafficking (incl. Child Labour)	0	1	1	2
Loss & Grief (Death of Parents and/or other Attachment Figures)	1	2	1	4
Alcohol dependency in parents	1	1	3	5
Parent with mental illness/ disability/ Health issues	0	0	1	1

Of the children assessed at the institution, 2 children were referred to the Dept. of Child & Adolescent Psychiatry, NIMHANS for ADHD, Substance Abuse and Runaway behaviours. These were children requiring further in-depth assessments in multiple areas as well as longer term in-depth psychotherapy. One of them was admitted to NIMHANS Child Psychiatry ward for further treatment.

b) Group Interventions.
During this quarter, the project has reached 24 children through 5 group sessions held in 1child care agency. As described in the previous quarterly report, life skills modules have been developed to address issues concerning emotional development, motivation for younger children between the age of 8-13 years. The project is conducted these sessions as per the availability of children in institutions. Table 2 (d) below shows the session content for each institution/group of children.

Table 2(d): Group Interventions Provided to Institutionalized Children, April-June 2016 2016

Institution	Session Content	No. of Children	Age Group
MakkalaJeevodaya	Rapport building: Who am I and who is everybody else?	13	9 to 12 years
	Feelings: Identification of feelings, Acting out feelings	13	
	Feelings Stories	13	
	Movie Screening: Stanley Ka Dabba	24	
	Separation and loss: Storytelling and discussions- Story on 'Ankit's New Family'	13	
Total No. of Children Reached		24	
Total No. of Sessions		5	

2.2. Interventions in Children's Institutions: Children with Disability

During this quarterly, the Project continued its work in the 2 child care institutions serving children with disability.

2 (e): No. of Children Reached in Disability Child Care Institutions

Nirmala Shishu Bhavan	13
Morning Star	34
Total	47

a) Nirmala Shishu Bhawan

In continuation of the project programme, the Project supported the trainee teacher in Individual Education Programs (IEP) implementation by exploring different methods to manage the challenges she faces in working with each child in the ways described below.

- Access to materials: The teacher was helped to list the various materials required by the children. Suitable storage spaces in the school room were identified and the teacher was encouraged to use those spaces as a trial. A satisfactory arrangement was arrived at. Materials like books, writing copies, basic stationery items and level

specific books were placed in individual bags. Other materials such as blocks, colours flash cards etc were stored in the shelves and cupboards in the room with the understanding that the teacher would lay them out on a table before starting the teaching sessions and put them away after class hours. Now that the teacher does not have to spend time searching for appropriate material for each lesson, her time management is far more efficient and the flow of the lessons is maintained.

- <u>Visitors during Class Hours:</u> No concrete step could be taken regarding this aspect. The decision whether to allow visitors during class hours is beyond the purview of the Project team and the trainee teacher. However, the facilitator has approached the Home authorities regarding this, citing it as a serious distraction. The authorities are willing to review the existing norms and make necessary changes soon.

- <u>Differentiated teaching:</u> The facilitator decided to use directive modelling for the teacher to emulate as seemed to find it difficult to redesign the existing class management norms. For these sessions, the facilitator requested the teacher to mimic the methods being demonstrated. The facilitator demonstrated class readiness activities by arranging all the materials required before beginning class. Then she distributed different materials among the children – colours and drawing book for one, slate and chalk for the next, building blocks for the third and fourth child. She then engaged the fifth child in a reading activity that she conducted on a one-on-one basis for 15 minutes. At the end of this session she asked the child to copy-write the words just read and moved to the next child to conduct a one-on-one reading session. She also changed the materials the other children were engaged with. In this way the facilitator engaged each of the children in one-on-one sessions for the reading activity, while the other children remained engaged with activities they could pursue more or less independently.

- <u>Use of Volunteers:</u> The project team used a unique method to demonstrate volunteer management methods to the teacher. The facilitator liaised with a boy, 16 years old, tasked with certain community service assignments as part of his counselling programme (also a Project initiative to assist children with conduct disorder/ in conflict with the law), to volunteer in the Home school room. The teacher was encouraged to guide the boy's activities as a volunteer, thereby learning to delegate activities to a volunteer and also guide the volunteer about the type and level of activity with each child.

- <u>School Holidays:</u> The facilitator encouraged the teacher to try and keep the external school children engaged with school tasks like school home-work and/or incomplete school class work instead of trying to design a completely different set of activities for them. Moreover, the facilitator forwarded the suggestion to the authorities that on days there are an increased number of children in the school-room, the teacher be granted extra help in the school room.

<u>Observations:</u>
The children continue to respond with great enthusiasm to the programme. Progress has been achieved in the following areas –
- ✓ Finger Grip ability – 2 children (holding and manipulating chalk piece/pencil/crayon/ small blocks)
- ✓ Staying on task – 5 children (from 2-3 minutes to 7-10 minutes)
- ✓ Independent work – 3 children (pursuing an activity without frequent requirement of assurance)

- ✓ Following instructions – 4 children (taking up a given task willingly)
- ✓ Enhancement of individual skill levels –
    - o Fine-Motor – 2 children (grasp and grip, pressure on surface, joining/ balancing toy blocks, pulling apart)
    - o Speech – 2 children (sound mimicry, reciting rhymes, one-word answers to conversational questions)
    - o Reading – 4 children (identifying sight words, syllabication and synthesis of phonetic words, fluency)
    - o Writing – 3 children (clarity of formation, accuracy in copying)

The teacher is motivated and encouraged by the tangible progress made by the children. She needs to be supported to help her practise differentiated teaching methods more effectively.

Next Steps:
- The project tem will continue in their efforts to negotiate with the Home authorities to bring about systemic and other changes that would better facilitate the home School programme.
- The teacher will be further trained to practically implement the IEPs. She will be supported in enhancing the differentiated teaching skills required for effective implementation of the IEPs through demonstration sessions and repeated practice under supervision.
- A time-table chart describing each child's individual routine and a skill-level chart describing each individual child's skill levels in each of the skill areas will be prepared by the facilitator in collaboration with the teacher, and displayed on the school room wall.
- The programme will be reviewed in October, 2016, through collated feedback from the IEP observations, the teacher the Home authorities and the Project team.
- Planning of the Home school programme for the time period of November 2016 to April 2017 will be done after considering the outcomes of the review.

b) Morning Star Ashram
The Morning Star Ashram is home to about 45 individuals with severe to profound intellectual disability of ages from 10 years to 40 years. Many of them also have physical disabilities and hearing-speech impairments. There are 5 permanent staff members who multi-task in the roles of care givers, teachers and all service providers. A few volunteers pitch in from time to time. Many of the individuals, depending on their abilities, also participate in cleaning and care giving roles.

Inputs to the Staff and Children:
The NIMHANS project team visited the Morning Star Ashram every 1st and 3rd Saturday, and has provided services 5 times till date. The first two visits were spent in orientation. The project member got information from the Home authorities about the routines and practices followed there, the requirements of the individuals. Their ability levels in different areas etc.
The 3rd and 4th visit was used by the project member for rapport building. The Project team spent some time with each individual to establish familiarity and methods of communication. Most of them respond to spoken language and some need gestures to facilitate language comprehension. Most of them responded favorably to gestures of friendship too. For the 5th

visit the project member worked with 4 children in the age group of 11 to 14 years, doing an activity of matching colour and shape. She used a set of plastic fruits that are cut in half with pieces of Velcro on one end of each piece. One half of a fruit would be held up, the colour and shape repeatedly emphasized and the child encouraged to find the other half. 3 rounds of matching was done with each child.

In each 2 hour session the facilitator worked with 3 children; thus working with 12 children in the 4 sessions. In each 2 hour session the facilitator spent about 40 minutes with an individual child. The activities engaged in were –

- Colouring
  (The facilitator offered a crayon and asked the child to colour a sheet of paper. Each child, who could participate, was encouraged according to individual abilities, to hold the crayon firmly/ apply suitable pressure to the paper/ choose a colour.)
- Matching by colour and shape
  (The facilitator used different objects like blocks, plastic fruits, pictures, cardboard cut-outs etc and asked the child to match 2 objects, either based on colour or similarity.)
- Throwing and catching a ball
  (The facilitator used a soft, cloth ball for the activity and asked the child to throw the ball as near the facilitator as he could. Then, the facilitator threw the ball at the child and asked the child to try and catch/touch the ball.)
- Rolling a ball towards a defined spot
  (The facilitator used a medium-sized plastic ball and asked the child to roll/push the ball towards her. After each turn the facilitator changed her position and encouraged the child to accordingly change his position.)
- Picture reading using flash cards
  (The facilitator used pictures of animals/trees/flowers/vehicles etc. She asked the child to look at the picture while she called out the picture's name. Then she handed the card to the child/guided the child's fingers and called out other details like colour, shape, size, use etc.)

Similar activities need to be practiced with the individuals to facilitate cognitive development.

Observations:
- Most of the children displayed signs of recognition when approached and addressed by the facilitator.
- 8 out of the 12 children show some signs of recognition when approached by or spoken to by the facilitator.
- 1 child is able to engage in the picture reading and matching activities with 80% accuracy, in the first attempt after watching the facilitator's demo.
- 4 out of the 12 children are able to engage in the picture reading and matching activities with 30% to 40% accuracy in the first attempt after watching the facilitator's demo.
- 8 out of the 12 children evince various degrees of interest and enjoyment in the ball activities whereas 4 of the children remain disengaged.
- The children would benefit further if the authorities could follow a structured regimen of engaging them with the said activities on a daily basis.

Disability Certification:
The Project team advised the authorities on the process involved and benefits of getting the individuals assessed for Disability Certification as an eligibility criterion to get the government disability grant from the government. The project team will facilitate the said assessment with help from the Dept. of Psychology, NIMHANS.

Challenges:
Activities similar to those described above need to be practiced daily with the individuals, to facilitate cognitive development. Repeated reinforcement of stimulation through the practice of these activities will provide the opportunity for developmental progress. It is recommended that the authorities assign a person to collaborate with the project team to be trained and guided regarding the activities, the methods of practice and the schedule of practice. In the absence of such a structure, the benefits of the program would be minimal. It has been observed that the institution currently does not have adequate human resource to support such collaboration. The facilitator's sessions, should serve as demonstration models, to be followed by one of the institution's care-givers. Bi-monthly intervention by the facilitator will not, in any effective way, serve the purpose of developmental enhancement for the children with Intellectual Disorder.

2.3. Interventions in Children's Institutions: Children with Chronic Illness

A key component of the Project's services is to assist children in difficult circumstances (CIDC), namely street and working children, orphan and abandoned children, children with disability, children infected/affected by chronic illness such as HIV and cancer. This is because these children are at higher risk of developmental lags and mental health morbidities due to their experiences of socio-economic difficulties, illness, and developmental disabilities.

Even within this group, children suffering from chronic illness form an especially vulnerable group with higher mental health and psychosocial risks. The project already initiated assistance to HIV/AIDS infected children through direct individual and group services (in select child care institutions and in IGICH) and training and capacity building activities for staff working with these children, and was keen to do the same for children affected with cancer.

The objectives of our support and services to children affected by chronic illness/ cancer are:
  i. To obtain a clear understanding of children's issues as well as the scope and feasibility of integrating mental health issues into the existing (cancer) treatment protocols through mental health screening processes.
  ii. Based on this initial scoping, to design mental health and psychosocial interventions and services for the children.
  iii. To provide mental health services, through individual and group interventions to children affected by chronic illness

In the initial 2 months, the Project focused on achieving objective (i) and (ii) so as to plan the delivery of objective (iii) i.e. the next stage of project implementation.

Thus, as part of the Project's objective to assist children in difficult circumstances, including children with chronic illness such as HIV and cancer, work was initiated at the Dept. of Paediatric Oncology, KIDWAI Memorial Institute of oncology, in the month of April 2016. This document first provides a brief background to understanding children with chronic illness, specifically cancer, and then describes the initial work done by the Project over a period of two months, April-May 2016.

A) Understanding the Psychosocial Implications of Chronic Illness in Children

Chronic illness is or medical condition defined as "a health problem that lasts three months or more, affects a child's normal activities, and requires frequent hospitalizations, home health care, and/or extensive medical care."[1] Specifically, definition of chronic health conditions in a child or adolescent is "any physical, emotional, or mental condition that prevented him or her from attending school regularly, doing regular school work, or doing usual childhood activities or that required frequent attention or treatment from a doctor or other health professional, regular use of any medication, or use of special equipment"[2].

Major advances in the diagnosis and treatment of chronic illness in children and adolescents have changed the outlook of clinical pediatrics. Diseases that were once fatal are now successfully treated and children survive at much higher rates than 20 to 30 years ago[3] These improved outcomes are based on early detection and diagnosis and powerful methods for the treatment and management of many previously life-threatening diseases. As a consequence, millions of children and adolescents now live with chronic illnesses and medical conditions including type 1 and type 2 diabetes, cancer, sickle cell disease, asthma, and chronic pain. These illnesses and their treatment present children, adolescents and their parents with significant sources of chronic stress that can contribute to emotional and behavioral problems and can compromise adherence to treatment regimens. Further, many pediatric illnesses are exacerbated by stress encountered in other aspects of children's lives. It is therefore essential to understand the ways that children and adolescents cope with stress to better understand the processes of adaptation to illness and to develop effective interventions to enhance coping and adjustment. Children with chronic illness have increased risk of developing behavioral and emotional issues[4]. It is therefore imperative to emphasize the importance of early detection of mental health issues in the children with chronic illness[5] such as cancer.

Chronic illnesses in childhood and adolescence are cause significant stress and are also affected by stress in other life domains. For example, a child who has been experiencing headaches and nausea is brought to the emergency room by her parents who assume that she is ill with the flu. The family is shocked when they are told that results of a scan identified a tumor in the posterior portion of her brain. She has to undergo immediate surgery to remove the tumor followed by an extensive regimen of cranial radiation therapy. This

[1]Mokkink LB, van der Lee JH, Grootenhuis MA, Offringa M, Heymans HS, Dutch National Consensus Committee Chronic Diseases and Health Conditions in Childhood. Eur J Pediatr. 2008 Dec; 167(12):1441-7.
[2]Van Cleave J, Gortmaker SL, Perrin JM.JAMA. 2010 Feb 17; 303(7):623-30.
[3]*Halfon N, Newacheck PW. JAMA. 2010 Feb 17; 303(7):665-6.*
[4]Lavigne, J. V. &Faier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: a meta-analytic review. *Journal ofPediatric Psychology*, **17**, 133–157.
[5]M. Hysing, I. Elgen, C. Gillberg and A. J. Lundervold (2009). Emotional and behavioural problems in subgroups of children with chronic illness: results from a large-scale population study, original article, Journal compilation © 2009 Blackwell Publishing Ltd

example reflects the challenges and stressors of serious chronic illnesses such as cancer, which are often unanticipated, uncontrollable and functionally impairing for children and their parents. Further, the acute medical events surrounding the diagnosis of a serious illness such as cancer are often the beginning of a long process of treatment and adjustment to a chronic condition.

Treatment of pediatric cancer can extend for months or years, followed by uncertainty about the threat of recurrence and the impact of often significant late effects in endocrine, cardiac, and **neuro-cognitive function**[6]. Thus, chronic illnesses present children and adolescents and their parents with the acute stress of a diagnosis followed by long-term chronic stress.

B) Kidwai Hospital Service Providers' Understanding of to Child Mental Health Issues

The Project initiated work in KIDWAI Memorial Institute of oncology, with the Dept. of Paediatric Oncology by first meeting with the treating team in the department in order to understand i) the treatment protocols and related hospital systems; ii) the knowledge and viewpoints the treating team has on the impact of illness on children's mental health. They reported that:

- The treating team tends to be very busy and pre-occupied with the treatment of the medical conditions as most children seeking treatment are already at critical stages of the illness.
- They have not observed any major mental health issues in the children they treat.
- Their only mental health-related protocol is for children above 5 years to be assessed for cognitive development before and after they undergo cranial radio-therapy.
- No particular protocols are followed for disclosure to children about the illness and that since the children reside in a large ward, wherein all of them have the disease, and 'most of them know that they have the disease and are even aware of the treatment protocols—for example, they know about bone marrow procedures, IT etc'.
- Most children are 'very sharp and intelligent' (since they know about the disease) and are usually 'happy'.

Having said this, some members of the team believed that there is a need for psychosocial assistance and because they have neither the time nor the skills, are perhaps unable to discern what children's psychosocial issues really are.

The hospital has a psychologist who serves the entire patient population, children and adults, and consequently also has limitations of time and coverage. A brief interview with her gave us to understand that:

- She mostly deals with children having leukaemia because it has a better prognosis (good survival rate) than other cancers, and that she provides a psycho-education package for parents.
- She usually sees the children after the first course of treatment (1.5 months after the treatment is underway) as children and families are 'busy with treatment procedures'.
- Some of the common mental health problems seen in children are bedwetting and temper tantrums and those seen in adolescents, are oppositional defiant disorder (mainly relating to medication adherence).

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[6] Robison LL, Armstrong GT, Boice JD, Chow EJ, Davies SM, Donaldson SS, Green DM, Hammond S, Meadows AT, Mertens AC, Mulvihill JJ, Nathan PC, Neglia JP, Packer RJ, Rajaraman P, Sklar CA, Stovall M, Strong LC, Yasui Y, Zeltzer LK. J Clin Oncol. 2009 May 10; 27(14):2308-18

- No specific illness disclosure protocol is followed; 'younger children may know that they have something called cancer but do not know the details'; 'adolescents know' so any additional questions they have are answered using psychological counselling sessions.
- Not much is known about children's reactions to mortality i.e. to children who die (in the hospital ward, although the treating team reported that this was a relatively rare occurrence).

In addition to the treating team and psychologist (both of whom are hospital staff), there is an NGO called Samiksha that visits the children's ward thrice a week to provide educational and recreational inputs to the children. The staff report that they are not aware of any emotional or behaviour problems in children.

C) Screening Children for Child and Adolescent Mental Health Issues

The Project began work by screening all the children before starting group sessions or individual depth sessions so that the team has better understanding of the systemic issues/ treatment protocol/ common issues/concerns of the children and parents. Thus, following meetings with the staff, the Project developed a child mental health screening protocol for children/adolescents & parents in order to identify children's psychosocial and mental health concerns (refer to annexes). Three types of screening proformas were administered:

i) For children age 7 to 15 years--administered to children, to understand their emotional experiences, their insight into their behavioural issues, knowledge and concerns about illness.
ii) For parents/caregivers of children aged 7 to 15 years--administered to parents/caregivers (mainly mothers) to understand their observations of their children's emotional and behaviour problems, concerns about illness and disclosure.

iii) For parents of children aged 0 to 6 years—administered to parents/caregivers (mainly mothers) to assess young children for developmental delays and disabilities in the 5 domains of child development (physical, speech & language, social, emotional and cognitive development).

During the Project team's visits to the Paediatric oncology- comprising of two wards, a total of 30 children, between age 7 and 15 years, 34[7] parents of these children, and 47 parents (mothers) of children between ages 0 and 6 years, were screened over the months of April and May 2016[8]. Subsequent sections of this report detail out (and analyze) the findings from the screening activity.

D. Findings and Analysis: Children aged 7 to 15 years
Each sub-head provides findings and analysis in two parts: children's reports and parents', so that the perceptions and viewpoints of both are reflected. This was done because relying on one or the other may not provide a complete or accurate picture of the psychosocial problems incident in this group. This approach is also based on children's right to express

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[7] A slightly higher number of parents than children were screened in the 7 to 15 year old group because some of the children were not willing to engage in conversations with the Project team (either because they were tired/ had just completed some treatment or were shy or anxious).
[8] A slightly higher number of parents than children were screened in the 7 to 15 year old group because some of the children were not willing to engage in conversations with the Project team (either because they were tired/ had just completed some treatment or were shy or anxious).

their feelings and views, to have their voices heard on the one hand; and on the other, to note parents' observations and experiences, also legitimate and necessary especially when children are young and may not have knowledge or insight about their problems.

D.1. An Overview of Emotional and Behavioural Issues in Children with Cancer

As per the children's report, 45 child and adolescent mental health issues were identified (one child may have more than one disorder) in this group of children, of which 27 (60%) were emotional problems relating to anxiety and adjustment disorders/ depression; 18 (40%) were behaviour problems such as Anger/ Aggression, Demanding Behaviour/ temper tantrums and Medication/ Adherence issues. (Refer Table 2 (f)). A higher number of 76 cases were identified by the parents' screening tool, of which 33 cases of emotional issues and 43 behavioural issues were detected.

Table 2 (f): Child and Adolescent Mental Health Issues in Children aged of 7- 15 years, April-June 2016

Child & Adolescent Mental Health Issues		Children's Report		Parent's report	
		No. cases n=45	%	No. cases	% n=76
Emotional Problems	Anxiety*	20	44%	19	25%
	Adjustment/ Dysphoria/ Depression	7	16%	14	19%
Sub-Total		27	60%	33	44%
Behavioural issues	Anger/ Aggression	7	16%	15	20%
	Risk of ADHD	NA**	NA	6	8%
	Demanding Behaviour/ temper tantrums	8	17%	15	20%
	Medication/ Adherence issues- Refuse for medication and treatment	3	6%	7	9%
Sub-Total		18	40%	43	56%
Grand Total		45		76	

*As a particular child may have more than one reason for anxiety to avoid repetition the highest number has been considered in order to avoid double-counting.
** ADHD was not an item on the screening tool administered to children, since they may not have insight on it.

A striking finding is that 44% of children report having anxiety while only 25% of the caregivers report that their children have this problem. This indicates that caregivers are often not aware of their children's anxieties or for various reasons (such as parents getting upset), children do not share their worries with caregivers. According to children's and parents' reports 16% and 20% of children have anger issues, respectively. That there is little discrepancy here as well as in some of the other behaviour problems shows that children have insight into some of their difficult behaviours.

The discrepancy between the numbers of mental health issues (cases) as per children's and parents' reports are due to parents having greater insight into children's problems (especially as many of these children are young) with regard to behaviour problems, namely ADHD, anger and demanding behaviour/temper tantrums. However, much of the discrepancy is accounted for by the difference in reports on anxiety.

Overall, children report having more emotional problems while parents report that children have more behavioural problems (than emotional problems). As in other contexts, most behaviour problems (except for neuro-developmental problems such as ADHD) especially in

children in difficult circumstances i.e. those with chronic illness, in this case, have their basis in emotional problems. For instance, demanding behaviours and temper tantrums may be due to children's insecurity and anxiety with regard to the uncertainty and overwhelming nature of the illness and treatments; children's anger may stem from feelings of distress and dysphoria regarding their illness.

D.2. Basis of Emotional Problems in Children

Within internalization disorders or emotional problems, which were a major proportion of psychosocial problems expressed by children, the screening explored reasons for and psychosocial contexts of anxiety and adjustment disorders/ dysphoria/ depression (refer to Table 2 (b)

Table 2(g): Emotional Problems in Children between aged 7- 15 years, April- May 2016

Child & Adolescent Mental Health Issues		Children's Report		Parent's report	
		No. of cases (n=45)	% of Cases	No. cases n=76	%
Emotional Problems	Anxiety*	20	44%	19	25%
	Adjustment/ Dysphoria/ Depression	7	16%	14	19%
Sub-Total		27	60%	33	44%

Table 2 (h): Basis of Emotional Problems in Children aged of 7- 15 years, April- May 2016

Psychosocial Context		Reasons for Emotional Problems (Anxiety/Adjustment/ Dysphoria/ Depression)	Children's Report		Parent's report	
			No. cases	% N=101	No. cases	% N=100
Family	Illness related	Concerns about going back home	9	9%	18	18%
		As a Response to Caregivers' Worries and Upsets	10	10%	10	10%
		Separation from Family	14	14%	19	19%
	Other	Loss and grief	3	3%	3	3%
		Parental Marital Conflict	2	2%	2	2%
Sub Total			39	39%	52	52%
School		Poor School Attendance and Going back to School	8	8%	10	10%
		Academic Difficulty before the illness	4	4%	4	4%
		Academic Difficulty due to hospitalization	6	6%	NA	NA
Sub Total			18	18%	14	14%
Illness		Treatment/ Injection/ Pain	20	20%	15	15%
		Child's fear before treatment pain	17	17%	18	18%
		Child is worried/ anxious about illness and prognosis	8	8%	NA	NA
		Child is worried/ anxious about hair loss	NA	NA	2%	2%
Sub Total			45	45%	35	35%
Grand Total			**102**		**101**	

Family Context

Anxiety caused in the context of family can be categorised in two sub-parts namely family concerns related to illness and family concerns related to other psychosocial context such as loss grief, marital conflict i.e. unrelated to the illness but that may exacerbate the stress of illness. In this group of children the reasons for anxiety in the family context Separation and being away from home missing other family members constitute the majority. Both children and caregivers report that the main causes of anxiety and adjustment as: parents' upsets and worries (10%) and separation from home and other family members (14% to 19%).

i) Concerns about Going Back Home

According to the children's report, 9% of the total concerns and worries of the children corresponds to concerns about going back home. Many children had questions and worries such as:

- *When will I go back home?*
- *How will people/other family member receive me?*
- *What should I tell them about where I had been/what illness I had?*
- *Will the relationships continue to be as they were before?*

According to the parents' report, 18% of the total children screened had concerns and worries about going back home. When asked about concerns of their children about going back home and missing their family, parents reported:

- *She is worried about going back home.*
- *He misses his grandmother very much; he has never been away from her.*
- *She misses her father, and starts crying suddenly.*
- *He wants to go back home.*
- *Children say: We have so many people back home, why have to be here all alone? Let's go back.*
- *What has happened to me? What to tell our relatives?*

The treatment protocol in children with cancer requires the children to stay in the hospital for at least 4-5 months away from home. Children therefore are forced to be away from the comfort and familiarity of home and home routines, and separated from loved ones. It is normal for children to feel anxious about change in place and routine and about separation from family; but this is compounded by a hospital environment, a routine that is characterized by not only uncertainty and unpredictably but by various (painful) treatment procedures, thus leading to anxiety and adjustment issues in children, particularly in the initial duration of their stay. Later on, many children gradually grow used to the new/ hospital environment, particularly as they are part of a larger community of children, so that these anxiety and distress symptoms may be less evident. However, the larger anxiety about 'when am I going home' tends to be a pervasive one, lasting the entire duration of the hospital stay.

ii) Separation from Family

Around 14% of the children reported that they are worried about them being away from family. They have often said:

- *I miss my father, everyday night I cry.*
- *I miss my grandmother she is the one I love the most.*

Some children also report that they are anxious when their mother/primary care giver is away for short periods of time within the hospital i.e. when she goes to bring food, for instance.

About 19% of parents reported that their children are often worried and upset that they are away from their family and are anxious when they are away for some time.

- *She always asks 'did appa call?' She misses him very much. He cannot stay here he has go back to work.*
- *He loves his grandfather, if he doesn't talk to him over the phone he doesn't eat properly. Every day he talks to his grandfather.*

Caregivers also report how some of their children like them to be around all the time and that their children experience fear and anxiety when they go away to do chores within the hospital for short durations.

From a child mental health perspective, all children feel some degree of separation anxiety in early childhood/ during a child's pre-school years, and this is normal at this developmental stage. However, as the child grows older (post age 6 to 7 years of age), such separation anxiety becomes a mental health problem which usually occurs in specific contexts of trauma such as child sexual abuse, domestic violence, parental marital conflicts. In such extreme contexts, children are afraid of leaving their caregivers even for short durations of time, and may also show 'clingy behaviour'. Children with chronic illness are also vulnerable to separation anxiety because: i) they tend to spend more time with primary caregivers than the average child of the same age and this may create greater attachment; ii) these children also have an increased dependency on their caregivers, especially considering that caregivers respond to children's illness needs. Consequently, they are less independent and more reliant on their caregivers for various needs (more than the average child) and experience fear when their caregivers are not around.

From our work, it appears that in children there are two types of separation issues: the first one is (temporary) separation from the primary caregiver even for short durations i.e. more akin to separation anxiety; the second one pertains to separation from other family members (some of whom may also be attachment figures—such as fathers/ grandparents). While the first type of separation is experienced more as anxiety, the second type of separation may be experienced more as a sense of loss. Younger children experienced both types of separation issues (anxiety and loss), while for most older children, their concern was not temporary or short-term separation from primary caregivers but separation from loved ones at home—so their experience was that of ,missing home and family and sadness about being away from fathers and other loved family members.

Having said that, some older children also do have some anxieties related to temporary/ short-duration separation from their caregivers within the hospital premises, and they need to be further assessed for separation anxiety.

iii) As a Response to Caregivers' Worries and Upsets

It was observed that about 10% of the total concerns and worries of the children corresponds to parents' worries i.e. children worry more and become upset when they know that their parents are worried and upset. When parents sometimes are extremely worried they cry, and children report they were worried and feel like crying.
Parents also corroborate this view.
Children often said:

- "When Amma cry, even I feel like crying"
- "If Amma is tense and worried I get worried that something is wrong"

Parent's often reported:
- "When I am tense and worried he asks me repeatedly what happened."
- "Whenever she sees that I am crying, she becomes very anxious and doesn't want me leave her alone even for some time."

When children see that their parents are worried and tensed they feel that something is wrong; this compounds their existing worries and concerns about their own health. It is a well-established fact that when there are worries and tensions in a family, felt or projected by adults, whether due to illness or death of a family member or marital problems or financial stress, children also reflect the worries of adults and caregivers; Even if they do not comprehend completely what the problem is (as in case of infants and very young children) and the fact that the adults/caregivers are worried and upset makes children feel fearful and upset. Frequent crying, thumb-sucking, nail biting, inattention (due to pre-occupation with worry), frequent complaints about body aches and pains (that have no medical basis), and oppositional defiant behaviours are some examples of anxiety-related behaviours that children develop in response to caregiver worries and tense home and family environments. (Worries and concerns of parents have been documented later in the report).

iv) Loss and Grief
A few children (3%) screened had suffered loss experiences in the family context, ranging from a few months to a fear years prior to (detection of) illness. A child who has lost an attachment figure and a primary caregiver is already vulnerable to emotional issues because these children invariably experience deficits of love and care, a sense of sense of loss and insecurity, for, losing a parent/ caregiver can never be a 'normal' experience for any child; and such loss impacts children's development, especially in socio-emotional domains. A child who has to contend with loss of a caregiver along with the experience of illness therefore is more vulnerable to anxiety and adjustment issues.

In some children the anxiety and feelings of vulnerability created by illness triggers the sense of loss (even if it has been some years since the loss event occurred) and get children to return to ruminating about the loss experience; difficult memories brought to the fore by the illness therefore exacerbate anxiety and distress. For children who may have had loss experiences more recently, they compound the anxiety and worries brought on by the illness adding to the emotional and psychosocial vulnerability. Also, the illness experience itself is a type of loss experience—loss of school days, play, friends and many other childhood experiences that normal, well children would otherwise have.

Further, loss of a parent impacts family and psychosocial systems and support that children would otherwise have access to; children with chronic illness/cancer need greater financial, systemic and psychosocial support than others and in the absence of these will be at risk of anxiety and other psychosocial problems.

v) Parental Marital Conflict
As we this was just an initial screening done in order to pick up major concerns and worries of the children in terms of illness and the treatment a detailed history of the family regarding

marital conflict domestic violence etc was not taken. However, some parents did report that there were marital conflicts. Given that children with chronic illness already have many anxieties about their illness, other stressors such as marital and family conflicts only exacerbate the (illness) worries and upsets.

School Context

In the group of children screened, around 18% of the total concerns and worries expressed by the children and 14% of parental concerns were about school and academics. When children and parents were asked what their concerns and worries about school, a majority of them reported that they are worried about going back to school: what to tell the friends, how will they be treated, and difficulty in their academics due to long absence.

i) Poor School Attendance and Going back to School

8% of the concerns and worries expressed by children were about going back to school:

- *Will I be treated differently by their friends and teachers because I missed so many days of school or due to their illness?*
- *What will they ask about my treatment/illness? And what to tell them?*
- *I haven't written my 7th final exam as I was in hospital. Now I have to study 7thstd again, all my friends will be in 8th std.*

Among the 34 parents, around 10 of them (a third) reported that their child is often worried and concerned about going back to school:

- *She is constantly asking whether he will go back to the same school.*
- *He says he does not want to go to the same school when he goes back.*
- *Children ask: What should I tell my friends if they ask why had I not come to school for so many days?*
- *She says she wants to go home so that she can go to school; she loves to go to school.*

Chronic illnesses such as like cancer and HIV adversely impact children's school attendance. While this issue might not seem critical to adults, for children, not being able to be to do the things that other children do (e.g. going to school, physical activity and games) is a major concern; added to this, having to take medicines, visit the hospital frequently, limit physical activities and games create a sense of otherness, and children feel very conscious that they are different from their peers. Hence, the worry about 'what to tell everyone' or the reluctance to disclose to others about their illness—and this includes the fear of being labelled in case their health status is known to peers and teachers[9].

When children are not able to do their final exams, detention in the same class create fears in children that they will be treated differently or made fun of by other children and some are upset that all their friends will be in a higher class while they will be still in the same class. Being left behind also means that these children have to make new friends and adapt to a

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[9] One critical difference between children with cancer and those with HIV is that the former have a non-communicable disease while the latter have a communicable disease that is also transmitted in ways that society tends to be more judgemental about (sexual transmission). Consequently, children with HIV tend to be more stigmatized than those with cancer. Also, they tend to be more discriminated against than children with cancer because HIV is a communicable disease and schools and parents of other children in school are fearful that other children will get the disease. Thus, while there are similarities, there are also great differences between children affected by chronic illness, depending on what the illness is.

new group of children. There is also a risk of stigma and discrimination by the new peers as the child has not moved to the next class.

We also noted that parents sometimes instruct children to not disclose about their illness to others outside the family/peers/teachers because of their own worries of stigma and discrimination; this increases existing anxiety in children who are already not quite sure of what to tell/ how to explain their long absence from school to their peers/teachers.

Apart from the socio-emotional anxieties that poor school attendance creates in children, there is the academic and developmental aspect. When children miss school for weeks and months, it is difficult to catch up when they return to school and to maintain their grade levels and performance. Difficulty with academics becomes an added stressor for these children.

ii) Academic difficulty in children Before and After illness

During the screening, the project staff checked for any kind of learning difficulties children may have had prior to illness detection and hospitalization and found that 4% of children reported they had some kind of learning difficulty before the illness was detected. Learning problems in children have many underlying causes ranging from specific learning disabilities, mild intellectual disabilities or dull-normal intellectual abilities or ADHD to emotional and behaviour problems and under-stimulation[10].

Even for those children with neuro-developmental disabilities and other pre-existing learning problems, but without medical problems, and who are able to attend school normally, academics can be difficult to cope with.

Children with learning difficulties and chronic illness have increased risk of learning problems and poor academic performance because of under stimulation and lack of opportunities for learning in the hospital setting[11]. About 6% developed learning difficulties after hospitalization. Children reported that:

- *I may find it difficult to score good marks in my tests as I have missed all the classes.*
- *After I go back to school I will have lot of homework, as I have missed school for 3 months now.*

Thus, long absences from the school create under-stimulation and lack of opportunities/ exposure to learning either creating learning difficulties or exacerbating existing learning disabilities. The anxiety created by learning problems and low academic problems, especially in the light of systemic/ teacher pressures to perform, places these children at higher risk of anxiety disorders such as school refusal and psychosomatic disorders.

Concerns about Illness

When children and parents were asked what their (children's) concerns are about the illness, they said they were worried about the treatment and the pain caused by it, children are often

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[10] Under-stimulation refers to lack of (educational) opportunities, never went to school, migration, change in medium, long absence from school.
[11] Sameeksha, the NGO, provides children with educational activities so that they can continue to learn while in hospital. However, in the current set up and on-going medical treatment, children do not attend classes regularly; also, the education activities are not geared to formal schooling needs of children i.e. the system they return to when they go home.

anxious and worried before few treatments such as Bone marrow and IT; few children also reported that they are worried about the illness and about whether or not they will be completely cured.

Almost 45% of the concerns and worries expressed by the children correspond to the anxiety caused in the context of the illness. Children's concerns include:
- *The treatment and the pain caused due to it.*
- *When will the treatment finish?*
- *Will it pain too much?*
- *Has the treatment procedure been successful?*
- *What kind of illness I have? Is it dangerous?*

About 35% of the parents reported that their child is often worried and upset about the illness and treatment:
- *He was a very happy child, always making jokes and talking to everyone. But now he is always worried and sad.*
- *She frequently asks me whether she will ever be cured of this disease.*
- *Even before 2 days of her Bone marrow treatment, she starts crying.*
- *She will be very anxious and worried before her investigation reports come.*
- *She is always worried and keeps on asking question about her illness to all the doctors who come in.*
- *He often say- why did this happen to me? And starts crying.*

Most of the children expressed that there major concerns and worries related to illness is treatment and the pain it causes. Children reported that they are often afraid and tense even before the treatment is done (i.e. 1 day prior to the treatment). When asked about the reasons for it they reported they are worried about the pain as well as the outcomes of their treatment (Usually Bone marrow procedure is done at the end of each phase, children are often worried about the outcome of the procedure. If the test result is not good, in the normal range, children will not be able to move to the next phase of their treatment. Hence, children are anxious and worried about illness, treatment and prognosis of the illness.

Thus, although hospital staff assume that children 'know' about the illness and can 'name' various treatments, and also that children are unafraid of treatment procedures, these assumptions are questionable. It is evident that children have questions and concerns about the nature of their illness; that being able to 'name' treatment procedures does not necessarily mean that they understand them; not articulating anxiety and fear about the illness, treatment and pain (especially since children are not asked) does not mean that they do not have these feelings about the illness.

On the other hand, a few of the children also reported that they feel happy when they have bone marrow procedure as it indicates the end of one cycle of the treatment; more importantly the count-down to going home can begin. (Subsequent sections of the document further discussed issues of illness and pain).

D.3. Basis of Behavioural Problems in Children with Cancer

This sub-section describes the basis of behaviour problems in children with cancer.

Table 2 (i): Behaviour Problems in Children between aged 7- 15 years, April- May 2016

Child & Adolescent Mental Health Issues:	Children's Report		Parent's report	
	No. of cases (n=45)	% of Cases	No. cases	% n=76
Anger/ Aggression	7	16%	15	20%
Risk of Attention Deficit Hyperactive Disorder	NA**	NA**	6	8%
Demanding Behaviours/ Temper tantrums including Oppositional Defiant Disorder (ODD) Behaviours	8	17%	15	20%
Medication/ Treatment Adherence issues-	3	6%	7	9%
Sub-Total	18	40%	43	56%

a) Anger and Aggression

16% of children reported having anger issues. When children were asked what makes them angry, they reported that they usually feel angry because their parents insist on their doing certain things and try to control their actions. They also reported that their anger is usually related to following certain dietary requirements, because their parents do not let them eat what they want or force them to eat what they don't like (most of them reported they don't like eating fruits).

Around 20% of parents reported that their children have anger and aggression issues. They report that these anger problems were noticed after their child was hospitalized. They often complained that their children get angry for relatively minor issues such as taking bath, eating, that they do not obey instructions, not even when requested politely. They state that they find it very difficult to manage such oppositional behaviour and requested assistance for this.

Usually, children who are suffering from illness, or under treatment and/or hospitalized, show anger and aggression, experienced because of the loss of health, school, routine and normal life. An illness like cancer which is protracted in nature and also includes series of painful treatments, creates lot of stress such as separation from family, the pain of the treatment, the frustrations of hospitalization and coping with unfamiliar, unpredictable environments. This emotional distress often manifests as anger and aggression in children. Further, when children are not given information about the illness in ways they can understand, not prepared for hospitalization and then subjected to invasive procedures, this also causes increased verbal and physical aggression in them. According to a study almost 71% of children between 6-12 years and 43% of 12-16 year olds were affected in this manner.[12]

b) Demanding Behaviour and Temper tantrums

17% of cases, as per children's reports, were found to have problems relating to demanding behaviour and temper tantrums. When children were asked "do you feel that since you are sick, your parents need to get/buy whatever you ask for?", some of them said:

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[12] Aisenberg RB, Wolff PH, Rosenthal A, Nadas AS. Pediatrics. 1973 Jun;51(6):1051-9.

- *As I have to take medicines and follow the diet, which is difficult, they should buy me whatever I ask.*
- *I am sick, so my parents get me whatever I ask for.*
- *If my mom doesn't get me ice cream I won't take the injection.*

According to parents' reports, 20% of the cases were identified with demanding behaviour and temper tantrums. Parents often said that they were frustrated and did not know how to handle their children when they are demanding. They said:
- *If I don't buy her what she asks, she won't eat.*
- *If we don't get him sweets/toys then he won't take medicines/injections.*
- *She threatens me that if I don't get her what she ask she will not take medications nor eat food. So I get her whatever she asks even though it is difficult for me.*

When children are sick, especially with a serious chronic illness like cancer, parents and caregivers feel a sense of distress as well as sympathy towards the child. Given the child's pain and deprivation of normal life and routine/ play and other pleasurable activities, they may tend to feel the imperative to compensate by meeting the child's demands, especially for material things (such as toys and gadgets, which are often what children demand for). Children then learn to use their illness to gain what they want and this knowledge is again put to use by making bargains with parents when painful treatment procedures need to be undergone; parents and caregivers also lure children into cooperating with treatment procedures children by offering gifts and treats. This imperative to give into children's demanding behaviours is thus compounded by the fact that parents are desperate for children to cooperate with the treatment and are willing to strike these bargains/ buy whatever it takes if children comply with treatment procedures.

That these children are really ill and deprived of a normal life is not in question at all. That loving parents and caregivers make all efforts to comfort them and meet their needs and try to compensate children for their discomfort is also not wrong. However, the issue is that temper tantrums and demanding behaviours are learnt behaviours and this learning, which was takes place in the context of illness, may be extended to other contexts and to greater proportions, which make it difficult for parents and caregivers to manage their children.

c) Treatment Adherence Issues
In this group of children, only around 6% of them (3 cases) reported that they have refused medication and treatment at least 2-3 times as the treatment was very painful and because they hate to take medicines. One of the children refuses any kind of oral medication but he is comfortable to take injections as is unable to swallow pills. Another child said he used to refuse to take medications in the beginning but he is used to it now takes the medication as it will help him to get well.

The WHO defines adherence to long-term therapy as "the extent to which a person's behaviour—taking medication, following a diet, and/or executing lifestyle changes—corresponds with agreed recommendations from a health care provider[13]. Unless the child adheres to the medication and treatment cure of the illness is not possible. Hence adherence to medication and treatment is critical. It is a well-established fact that nobody

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[13]Sabaté E, editor. , ed. *Adherence to Long-Term Therapies: Evidence for Action*. Geneva, Switzerland: World Health Organization; 2003.

likes to take medication and it especially true in case of children, who due to their developmental immaturity, lack the understanding the importance of medication and sense of responsibility as adults.

One of the reasons that adherence to medication and compliance with other treatment processes may not be an issue for these children is the fact that they are in hospital. Given where they are, they have little choice in treatment matters i.e. even if they were to refuse, they would be coerced into taking medications and treatments. How the treatment compliance and adherence plays out at home, when there are no enforcement systems may be another matter. The fact that a lot of temper tantrums and demanding behaviours are centred around medication/ diet and treatment adherence issues also indicates that children do have treatment compliance and adherence problems—they are, in their current circumstances, masked by the hospital systems and its requirements and by parental behaviours that pander to children's demands and conditions for taking treatment.

d) Attention Deficit Hyperactivity Disorder
Attention Deficit Hyperactivity Disorder is a common neuro-developmental problem that underlies certain difficult behaviours in children, namely restlessness, inability to sit in one place/ engage in and complete tasks, disruptive behaviours, poor social skills and judgement, impulsivity, emotional dysregulation (including poor anger control). Therefore, the screening process sought to identify children with ADHD so that their behaviours, which are attributable not only to illness but a neuro-developmental provlem, may be addressed appropriately.

In order to identify children with ADHD in the children, parents were asked a few (screening) questions regarding the child's attention, activity level and impulsivity. Of the 34, 6 children (8% of the total mental health issues) were identified with ADHD or risk of ADHD (to be confirmed upon depth assessment).

As in any normal population of children there will be certain percentage of children with neruro-developmental disabilities such as ADHD irrespective of the chronic illness. For a child who is already neuro-compromised, inadequate stimulation and learning opportunities, and particularly of structured activities and routines, as happens with chronic illness and hospitalization, will exacerbate the ADHD symptoms. Children with ADHD already have emotional regulation issues, so those with chronic illness which brings its own set of emotional concerns, may have more severe problems such as temper tantrums/anger and aggression issues, making these children increasingly difficult for their parents to manage.

In older children or adolescents, ADHD manifests in the form of poor social judgement, poor decision-making and impulsivity, all of which lead children to engage in high risk behaviour such as substance abuse, risky sexual behaviour and maladaptive coping strategies. Thus, untreated ADHD symptoms combined with the psychosocial effects of illness i.e. anxiety and dysphoria, makes such children prone to high risk behaviours.

Like in case of parents of children having demanding behaviours and temper tantrums, parents with ADHD children were not aware of their child's additional child mental health issues and have considerable difficulty managing them. In fact, parents of ADHD children with chronic illness found it even harder to set limits or enforce discipline than other parents.

Thus, interventions for ADHD are crucial as if they are not done it further facilitates and compounds other difficult behaviours in these children.

D.4. Illness and Disclosure

Disclosure essentially means providing information on the illness to children in such a way that they understand it and at the same time, are reassured that the illness is manageable if certain efforts are made by them (adherence to medication and adopting appropriate life style) to treat and control it. With increased survival rates (the 5-year survival rate for children with Acute Lymphoblastic lymphoma is up to 85% with the best facilities available), one of the greatest psychosocial challenges that parents and caregivers of children with cancer face is how to talk to children about their illness. Cancer disclosure entails communication about a potentially life threatening illness, and caregivers fear that such communication may create distress for the child.

In Kidwai Hospital, out of the 34 children (between ages 7 and 15 years), 33 of them i.e. nearly all had at least some knowledge about illness. This is more in the nature of some information about the illness—in our observation (and as per hospital staff reports), children were able to name the illness (cancer). However, this knowledge was largely come by 'on their own' or not through a direct conversation or planned interaction with the hospital staff/ treating team or with the caregivers.

Table 2(j): Disclosure Status of Children aged 7-15 years

Disclosure Status	No. & % of Children (N=34)
None	0
Partial	33
Full	1
Total	**34**

*No. of children=34 as this information was provided by parents (all 34 parents responded).

Surprisingly, parents tend to tell their younger children that they have cancer. Parents state that they do so because they feel that the children do not have the knowledge to really understand and process the serious nature of the illness (and therefore are less likely to be upset or distressed). Similarly, parents also do not tell older children about the illness because they are afraid that children will understand more about the disease and generally know more about it (and therefore are less likely to be upset or distressed). Thus, contrary to the disclosure framework, wherein younger children may receive limited or less information about the illness, and older children, given their higher cognitive capacities are given more information, in these hospitalized children, younger children are more likely to be told their illness diagnosis and older children are less likely to have details of their illness given to them—thus, these disclosure decisions are not based on children's rights or need to know, but rather on parental concerns and worries about the distress children are likely to feel upon knowing their diagnosis/ illness facts.

The Project team was also told that 'children know' because 'everyone here has cancer' and 'they hear all the time about medical procedures'. In a system wherein disclosure does not happen in a discreet session with a doctor/parent, with follow up sessions/interactions with the child to address his/her concerns/questions and disclosure depends on general hospital environment (other children and parents), there are several issues that may arise: i) Even if no direct disclosure has been made, the fact that the children are in the hospital for long

periods of time, undergoing various (painful) treatment procedures mean that children, especially older children, certainly know that they have a serious illness; ii) not telling them what it all about and providing detailed information about the illness can only mean that they receive half information, at times perhaps incorrect information based on hearsay and then what they assume or interpret; iii) since the ward comprises of many children and parents with the same kind of illness children hear and pick up bits and pieces of information and apply to their own condition which may be incorrect and create unnecessary anxiety and distress in children--because while there might be similarity in children's illness and the treatment protocol, the severity of illness, survival rates, and other vital conditions will vary, so allowing for unmonitored unstructured disclosure may cause misinformation; iv) children's family contexts, socio-emotional and cognitive capacities and temperament may vary, all of which affect how they process and respond to illness-related information; v) All these issues are likely to create scope for greater anxiety and distress than if children were to be engaged in planned processes of disclosure, to ensure correct and complete information-giving and allowing for questions and confusions to be clarified.

When children were asked whether they had any questions related to hospitalization and about their illness a majority of children, 53% (16 children) reported said they had questions and queries. 7 children (23%) were not sure whether they had any questions—these were younger children between age of 7-9 years. Another 7 children (23%) said they do not wish to know as it may create unnecessary anxiety and tension in them and they do not want to worry or be depressed about the illness. Interestingly, most of the children who said that they do not wish to know are above 10 years. This indicates that these children are already worried/ anxious and in actual fact have questions and concerns about their illness.

Table 2(k): Children's Need for Disclosure

Presence of Questions/ Queries about Illness	No. & % of Children (N=30)
Children having questions/ wanting more information	16 (53%)
Children who refused more information	7 (23%)
Children who were not sure	7(23%)

*No. of children=30 as this information was provided by children (not all 34 children responded).

Disclosing that they have cancer 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, caregivers' silences or diversionary methods can often worsen the anxieties and fears of a worried child—as is evident from the children's reports on illness concerns and parental worries. Providing half answers or brief responses or generalized sweeping reassurances as a one-off response to the child's questions also does not help. Reliance on children's observations and experiences of illness in their families and/or peer disclosure only allow for misperceptions and fears to build. And when concerns about their future and mortality are unanswered, they escalate and result in serious mental health problems such as depression and self-harm.

According to literature on illness disclosure in paediatric oncology, prior to the 1970's children living with cancer were given limited information about their diagnosis and prognosis. It was thought that they would have little understanding of the illness. Many thought it would be best to protect them from the emotional burdens their parents faced. However, in the 1970's several factors led to more open illness-related communication to children living with cancer, including: 1) improved survival rates, 2) the growing children's

rights advocacy movement[14],3) the increasing need to enlist children's cooperation with difficult research protocols and aversive treatment regimens, and 4) the results of psychological research pointing to a continuum of cognitions through which children orient themselves to illness and death.[6]Also Waechter[15] found that children show acute awareness of, anxiety about, and preoccupation with their condition despite their parents' stance of protective communication[16,17].As providers challenged the notion of withholding medical information from children, studies consistently showed that open communication about cancer diagnoses improved children's psychological adjustment, with the positive effects lasting into adulthood for both the child and family members[18]. By the early 1990s, the critical question was not "Should the child be told?" but rather "How and when the child is told?" Several groups of investigators began to demonstrate that diagnostic disclosure to children is generally most successful if accurately mapped to their cognitive and emotional development.[19] Disclosure may be seen as an on-going process as the child develops cognitive, psychological, and spiritual awareness about the meaning of illness and death.[20] Based on the studies about disclosure of HIV[21,22,23,24]preliminary work suggests, however, that children who know their HIV status have higher self-esteem than infected children who are unaware of their status.

D.5. Treatment and Pain

One of the attempts made during screening was to understand the degree of pain experienced during various treatment procedures children undergo. Both children and

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[14]Gaylin W, Macklin R, editors. Who speaks for the child? The problems of Proxy Consent. New York, NY: Plenum Press; 1982.

[15]Waechter E. Children's awareness of fatal illness. American Journal of Nursing. 1973;71:1168–1172. [PubMed]

[16]Spinetta JJML. Death anxiety in the outpatient leukemic child. Pediatrics.1975;56:1034–1037.

[17] Claflin CJ, Barbarin OA. Does telling lies protect more? Relationships among age, information disclosure, and what children with cancer see and feel. Journal of Pediatric Psychiatry. 1991;16:169–191.

[18]Katz ER, Jay SM. Psychological aspects of cancer in children, adolescents, and their families. Clinical Psychology Review. 1984;4:525–542.

[19]Bibace R, Walsh ME. Development of children's concepts of illness.Pediatrics. 1980 Dec;66(6):912–917.

[20] Disclosure of the diagnosis to a child with cancer should be individualized to include the child's cognitive ability, developmental stage, clinical status, and social circumstances. Thus, the stages of disclosure are not based only on age and children's cognitive capacities to receive information but also on children's socio-emotional readiness to process such information. Therefore, disclosure is an iterative process where each interaction and discussion between the counsellor and child or caregiver and child takes into consideration the previous one, the information that was imparted at that time and the child's processing and understanding of information already provided before new/ additional information is provided. It may also entail re-iterating and repeating previous disclosure content, for, young children may forget or still be unclear about what was shared the last time. And this brings us to the final point about disclosure: that it needs to be centred on the child and child's needs. According to HIV literature, there are three stages of disclosure (which can also be adapted in disclosing children about cancer):
   o   No disclosure (age 0 to 4): when the child is completely unaware that he/ she has been diagnosed with illness.
   o   Partial disclosure (age 5 to 9): when the child is aware that he/she has a chronic illness and is taking daily medications for it/ undergoing treatment.
   o   Full disclosure (age 10 and above): are capable of receiving full disclosure of illness, with more detailed information on mortality and other aspects of life affected by illness.

[21]Lipson M(1994) Disclosure of diagnosis to children with human immuno-deficiency virus or acquired immuno-deficiency syndrome. J DevBehavPediatr. 15:S61–S65.

[22]Grubman S, Gross E, Lerner-Weiss N, et al. (1995) older children and adolescents living with prenatally acquired human immunodeficiency virus infection. Pediatrics. 95:657–663.

[23]Lipson M(1993) What do you say to a child with AIDS? Hastings Cent Rep. 23:6–12.

[24]American Academy of Pediatrics.Confidentiality in adolescent health care. *AAP News.* April 1989:9

parents were asked to name which treatment procedures children found the most painful and feared the most. Out of 34 children 24 of them or 80% reported bone marrow procedure is the most painful among all the procedures. Children were also asked to rate the pain of the most painful procedure by asking them to Look at the pain thermometer and tell us, for most of the times how painful is their treatment?

Out of 30 children 17 of them or 57% rated their pain between 0-5 on the pain rating scale; and 13 of them or 43% rated their pain between 6 and 10 on the scale. When children were asked whether the treatment procedures are very painful they often reported that the pain which they felt in the beginning was unbearable, now as they are used to it, they just feel pain for some time. Few of the children also reported that the pain which they feel is only for few hours after the procedure.

Table 2 (I): Children's Pain Reports for Various Treatment Procedures

Procedure Reported to be Most Painful		No. & % of Children Reporting Pain (n=30)
IT		4 (13%)
Bone marrow		24 (80%)
VCR		1 (3%)
Injections		2 (7%)
Radiation		2 (7%)
Pain Rating Scale	0 to 5 level	17 (57%)
	6 to 10 level	13 (43%)

D.6. Parental Issues

a) Over-Protection:
Parental overprotection has also been associated with adjustment outcomes in children with chronic illnesses. Parental overprotection has been variously defined and conceptualized as overindulgent, over-solicitous, overprotective, and overanxious parenting[25]. In the parental overprotection literature, an overprotective parent is generally described as one who is highly supervising, has difficulties with separation from the child, discourages independent behaviour, and is highly controlling[26]. Based on various studies it is evident that children raised in an overprotective environment may be at increased risk for anxiety and depression later in life (e.g., Parker, 1983). Parents of children with a chronic illness, including cancer, may be over-protective because they perceive their child to be vulnerable as a result of their medical condition, or because they are attempting to gain control over a complex and unpredictable medical situation.

During the screening parents were asked "All parents worry when they have sick children. In your worry/concerns about the child, do you often insist on being with him/her all the time? Do you tend to restrict his/her activities like not wanting him/her to do too much physical activity or play, for instance? Do you feel anxious to leave your child alone even for short duration?"

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[25] Levy, 1931; Parker, 1981; Parker, 1983
[26]Thomasgard& Metz, 1999

Table 2(m): Extent of Over- Protection by Parents of Children with Cancer, April-May 2016.

Parent's concerns		No. & of parents (N=34)
Overprotection	Low extent	4 (12%)
	To some extent	23 (68%)
	High-Extent	7 (21%)

A majority of 68% of parents reported that they are over-protective to some extent; only a minority of 12% said that reported to high extent while one-fifth or over 20% parents reported that they are over-protective to a high extent. One limitation of this data is that these are parents' perceptions and reports, which may also be biased and therefore not entirely accurate. However, it is significant that a majority of parents do acknowledge that they tend to be over-protective.

It is a well-established fact that parents of children with a chronic illness, including cancer, may overprotect because they perceive their child to be vulnerable as a result of their medical condition, or because they are attempting to gain control over a complex and unpredictable medical situation. Recent studies also suggest that parents of children with a chronic illness manifest more overprotective, controlling, and directive behavior than parents of children without a chronic illness. Research on overprotection in the context of childhood illness found that once a child had recovered from an illness and regained his or her previous capacity for self-regulation and independence, some parents were unable to permit their child to regain his or her autonomy. These parents retained an overprotective attitude toward their child long after the child had recovered from his or his illness[27].

However, excessively protective parenting can be problematic, since it restricts the child's exposure to age-appropriate independent activities and may create excessive dependency in the child and even cause children to develop separation anxiety (already discussed in earlier sections of this report). Further, when parents, due to their over-protectiveness, limit children's social activities, children's social and interpersonal skills are compromised and may not develop age-appropriately. Limiting physical activity and mobility may prevent children from developing skills in other areas of child development, such as loco-motor skills (especially in young children), and cognitive skills (through limited access to avail of education and learning opportunities); consequently, children's socio-emotional skills are adversely impacted as they suffer poor self-esteem and identity issues.

b) Parents concerns and Worries

A key aspect of emotional development in children is learning how to regulate emotions. Children observe how their parents display emotions and interact with other people, and they imitate what they see their parents do to regulate emotions[28]. For example, children more prone to negative emotions or episodes of anger are deeply affected by hostile and neglectful parenting, often leading to even more behavioural/ emotional problems. Also, mental states of parents and care-givers influence the quality of parenting and care-giving they are able to provide the child with. For instance, a depressed parent is less emotionally available to a child and less able to respond to a child's socio-emotional needs than a parent who is not depressed.

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[27]Sameroff&Emde, 1992
[28]Sheffield Morris, A., Silk, J. S., Steinberg, L., Myers, S. S., & Robinson, L. R. (2007). The role of the family context in the development of emotional regulation. *Social Development*,*16*(2)

Hence, in order to further understand the child's emotional and behavioural responses and examine the quality of parenting and support available to them, a screening of parents was done, to understand their concerns and worries was done. Major concerns and worries of the parents with respect to child's illness, child's behaviour, about the disclosure of illness and the survival chances of the child were elicited (refer table xx for further details) and will be addressed through interventions for parents at a later stage of the Project implementation.

During the screening it was observed that almost 94% of the parents reported that they feel depressed due to the child's illness, 91% of the parents were concerned about the child's survival chances, 70% of the parents were worried about disclosure issues (what to tell the child about the illness and when to tell the child).

Table 2(n): Worries and Concerns of Children with Cancer, April-May 2016

Parent's Concerns/ Causes of Negative Emotional States	No of parents	% n=34
Child's Illness	32	94%
Frustrated with child's behaviour/ADHD/temper tantrums.	5	14%
Telling the child about illness/addressing child's concerns and questions- Disclosure issues.	24	70%
Survival chances of the child.	31	91%
Child's Future: Will the child be able to lead a normal life(social/education, family).	15	41%
Care of family/home other siblings	17	47%
Stigma and discrimination in family and society	4	11%
Financial Issues	20	55%

a) Feels Depressed due to child's illness

As is a well-known fact, parents are worried and depressed when their children are ill. 32 parents out of 34 (94%) reported that they are depressed by the child's having the illness, and often and feel like crying. Some of the mothers also cried during the interview. Mothers reported that:

- *I often feel very upset and want to cry, but can't cry in front of my child.*
- *I don't know what to do when I am upset, I just go out and cry.*
- *He was a very healthy child, never even got fever why did this happen?*
- *Nobody in the family have this disease, why did this happen to my child?*
- *They have told he will be alright, but I am very worried.*

The only 2 parents not worried about the child's illness, it was found, were not aware of the seriousness of the illness/ or even the exact nature of illness their children were diagnosed with. They also came from remote villages, and were not literate.

b) Frustrations with Children's Behavioural Issues

Among this group of children 14% of the mothers reported that they found it exceedingly difficult to manage their children's behaviour and were therefore very frustrated. The children of these parents had behaviour problems of temper tantrums and Attention Deficit Hyperactivity Disorder (ADHD). They reported that:

- *I sometimes feel like locking her up and hit her, later feel bad about myself for thinking like that.*
- *She is so adamant, if I don't get her what she wants she screams and sits on the road, don't know what to do.*
- *He is very stubborn, if he doesn't get what he wants he will hit me use bad language in front of everyone.*

As explained elsewhere, for children with difficult temperaments and problems such as ADHD, the illness and treatment procedures/ long hospital stay may increase emotional dysregulation and compound existing behaviour problems, making them exceedingly difficult for parents to manage them. Disciplining sick children can be a hard choice for many parents to make and so parents of cancer-affected children having behaviour problems, oscillate between guilt and helplessness.

c) Dilemmas of Disclosure

When the parents were asked about their concerns, a majority of them 24 (70%) reported that they are worried about whether they should tell their child anything about the illness, what to tell the child about the illness, how to tell, how much to tell, and when to tell. They were deeply concerned about how children are privy to all kinds of discussions and information by virtue of over-hearing other caregivers' and staff's conversations about other children and their illness; most of these were mothers of children above the age of 8 years, and were worried about how their children were processing and interpreting what they heard, including the implications of children picking up bits and pieces of information and applying it to their own condition, whether or not applicable. They reported that:

- *Even if we haven't told anything to our child about the illness, he has heard others talking.*
- *Few of the mothers don't understand what to talk in front of children.*
- *Parents of younger children don't care about what they are talking, they just discuss freely about the illness. My son now knows what is cancer, and since then he is upset.*
- *When we go to OPD children pick up information read signs and they understand.*

The importance of planned, systematic processes of disclosure and the implications of not disclosing or incomplete disclosure have already been discussed. It is evident that disclosure is not only an issue that pertains directly to children but also forms a major concern and source of consternation for caregivers. Parents also need to be part of the disclosure process i.e. through encouraging them to tell children about the illness, and helping them provide age-appropriate information to their children at every stage.

d) Concerns about Child's Chances of Survival

Among the 34 parents 31 of them (91%) of them reported that they are worried about their child's survival chances given that the child has been diagnosed with cancer. Even with advanced treatment and facilities the 5-year survival rate for children with ALL is only around 60-70%. Parents are not confident of the child's recovery even for a child with good prognosis as the very word 'cancer' spells impending dome for the child. Lack of proper disclosures methods which involve parents counselling etc. coupled with the lack of awareness in the parents about the illness results in more anxiety in the parents regarding their child's survival chances.

e) Worries about Children's Future

Around 41% of the parents were concerned about their child's future--whether their children would be able to lead normal lives socially, educationally, and family-wise. They were concerned that:

- *Will my child be able to study and go to school?*
- *Will he be able to play like other children?*
- *Will she be able to be normal, just like how she was before the illness?*
- *Will he be able to get a job in future?*
- *Will he/she be able to get married and have children?*

Concerns about the future are linked to illness prognosis, mortality, relapses, long term treatment, side-effects of medications, chances in the relationship market (whether a person with chronic illness will be acceptable in the marriage market). All of these issues form agendas for parent counselling and psycho-education so that their present anxieties pertaining to future issues can be alleviated.

f) Care of Home, Family and Other Children

Due to the hospital rule that only female caregivers can be with the children in the ward, most of the children are accompanied by their mothers and few children are accompanied by aunts or grandmothers. As mentioned, children have to stay in the hospital for relatively long periods of time i.e. 4 to 6 months, to complete the course of treatment. Since most of them were mothers, who are primary caregivers within their families, they were anxious about the running of the home and family in their absence, and in particular about care of their other children. 47% of the mothers reported that:

- *I have a very young daughter she is just 8 months old, I am often worried about her.*
- *My father in-law is very sick, he needs hospitalization as we are here we are not able to attend to him.*
- *I have 3 other children younger than him, have left them in my relative's place I don't know whether they are taken good care.*
- *I have a younger son who is very adamant and difficult to manage, I don't know how my family managing him.*
- *I have never left my children alone even for 1 day, my son is very upset that I have left him and come here.*

g) Stigma and discrimination in family and society

A minority of 4 parents (11%) were worried that their children might be at risk of stigma and discrimination by the society including school/ extended family/ neighbours. Parents were concerned that relatives and neighbours might not want their children play or interact with their own child. They were also concerned that their child might not receive the same opportunities at school i.e. that in being sympathetic even to the child's illness the school may discriminate against him/her—'He is sick, don't take him in sports/cultural activities'. However, as mentioned elsewhere in this report, the stigma and discrimination issues for children with cancer are nowhere near what is suffered by children with HIV/AIDS (people are aware that the latter is a communicable disease, also obtained through sexual routes; both these make HIV a far more stigmatized disease than cancer).

h) Financial Issues

Even with free treatment provided by Kidwai Hospital, there are other expenses incurred by families for care of their sick children such as when they buy fruits, juices, other foods children want to or need to eat. These costs amount to over Rs.200/day. Most of the children admitted are from low socio-economic strata and thus, almost 55 % of the parents reported that they had financial problems and many stresses result from this too.

D.7. Children who need further assessments and interventions

Based on the screening done, 17 children (50%) need further assessment and interventions for various mental health issues. (See Table 7 below).

Table 2 (o): Mental Health Issues of Children Requiring Depth Assessments

Mental Health issues	No. of children
ADHD	3
Depression/Adjustment	7
Anxiety	6
Anger aggression	1
Total	**17**

Findings and Analysis: Children aged O to 6 years

A total of 47 children were assessed aged 0-6 years. Of these, 7 children were aged 0 to 2 years and 40 children were between 3 to 6 years.

Table 2 (p): Demographic Details of Children aged 0 to 6 years, April-May 2016

Age Range	Male	Female	Total No. of Children
0-2y	6	1	**7**
2-6y	28	12	**40**
Total	**34**	**13**	**47**

Developmental Delays and Deficits

In this group of 47 children between ages 0 and 6 years, 39 cases of child mental health issues were identified. Only 1 child had physical developmental delay, and 2 children had speech and language delay.

The fact that there were no children with deficits in social development, is interesting because usually, children with chronic illness/ who are hospitalized, due to isolation, lack of mobility and limited peer interactions are at greater risk of developing social development deficits. What might account for this not happening in Kidwai, is that these children are in a large general ward type of setting. Consequently, they are constantly surrounded by other children (and adults) and so they have continuous opportunities for play and other social interactions. Moreover, since all the children are ill with cancer, there is no stigma and discrimination felt by these children, and thus no risk of social exclusion either.

Table 2(q): Child Development and Mental Health Risks in children aged 0-6 years, April-May 2016

	Developmental Domains and Issues		No. of Cases (n=39)
Child Development: Delays & Deficits	Physical/ Motor Development		1 (3%)
	Speech and Language Development		2 (5%)
	Emotional Development		27 (69%)
	Social Development		0
	Cognitive Development		0
Other Child Mental Health Risks	ADHD		7 (18%)
	Learning Problem		2 (5%)
Total No. of Cases			39

*Note: As few of the children have more than one mental health issues. The table shows number of cases, not number of children.

Table 2 (r): Emotional Problems in Young Children with Cancer

Temper Tantrums	19 (70%)
Separation Anxiety	6 (22%)
Anxiety	2 (7%)
Total No. of Cases	27

What is striking is that a majority of children, nearly 70% of them, have emotional problems. Of the 27 children (69%) with emotional problems, 19 (70%) children displayed Temper Tantrums, 6 (22%) of children had Separation Anxiety issues and 2(7%) of children had begin to show fear and anxiety.

Temper tantrums are one of the most common behavioral problems in younger children. They become problematic when they are frequent and/or unmanageable by caregivers. Generally, any experience of illness (even short-term normal childhood illnesses such as fever and respiratory infections) in young children makes them cranky and easily irritable. Given that at this age, children's speech and language abilities are limited or still developing, their ability to express their pain and discomfort is low and thus leads to greater frustration and crying.

The caregivers in Kidwai said that temper tantrums took the form of kicking, throwing objects, shouting, screaming and crying. Such behaviors were noticed mainly a during meal time and treatment process (which is probably when children feel discomfort and pain). A few parents reported that temper tantrums had increased after coming to the hospital and some of them felt that children were learning such behaviors from other children. Parents find very difficult to manage temper tantrums behaviors and thus their distress and frustrations are exacerbated.

Parents of children also reported that separation anxiety had increased after coming to hospital. Some of the behaviors reported were – children always clinging to mothers, wanting the mother to be with them all the time, even during classroom/ recreational activities. Separation anxiety in children necessitates primary care, namely mothers (who are the caregivers in the Kidwai ward) to have to be with their children all the time or as in case of young children, to carry them around all the time. This is stressful and tiring for the already over-burdened mothers and adds to mothers' distress and frustrations. Studies have also

found a strong relationship between the child's behavioural problem and parents' depressive symptoms[29].

Child Mental Health Risks

Children screened in the 0 to 6 years age group are very young and still developing certain abilities and skills, especially in the areas of learning and cognition. Therefore, for pre-schoolers, the screening sought to assess the risks of children developing learning disabilities and ADHD. 7 (17.94%) children have been identified with Attention Deficits and Hyperactivity Disorder (ADHD) risks and 2 (5.1%) of the children with Learning Disorder.

As stated earlier, ADHD is a neuro-developmental disability that in young children manifests as inattention, hyperactivity and impulsivity, which affect their learning and academics as well as their social development/ peer relationships. These children require a lot of training/ attention enhancement tasks and structuring of their day and time, all of which are difficult in a hospital setting, and especially as they are unable to go to school. In such a situation, children's ADHD problems could worsen—more so as emotional dysregulation caused by ADHD is exacerbated by the chronic illness experiences and parents find it hard to set limits for behaviour and following of daily routines.

Apart from ADHD, there are other issues that cause learning problems in children. 2 of the parents of young children, who did not report any cognitive deficits in their children, said that their children are not able to remember rhymes and that they avoid reading and writing. This indicates that these children may have learning difficulty—either due to under-stimulation (lack of opportunity to attend pre-school/ to gain readiness skills) or due to anxiety, or a combination of both; or they might have specific learning disability, which neuro-developmental disability—but that can only be diagnosed at a later stage, once adequate learning opportunity and stimulation has been provided to the child.

Children with chronic illness because of long absence from school, illness-induced stress, constraints on physical and social activities and decreased expectation from the family, school are at a high risk of learning disorder or difficulties[30]. Most of these children have not had any preschool education. They would be under stimulation for the development of fine motor and cognitive skills As a result many of them would be likely to develop problem in readiness skills for reading and writing. In case there is co morbidity condition of ADHD children may experience greater problems with learning maths, reading and writing[31].

E. Recommendations for Psychosocial Care Interventions

Based on the findings, the needs and concerns reported by children and their caregivers, below are our recommendations for psychosocial work with hospitalized cancer-affected children.

E.1. Screening and Identification of Mental Health Problems

With a view to identifying emotional/ behaviour problems & developmental disabilities, all children admitted to the children's ward at the hospital should be screened. It is recommended that this mental health screening is completed within a week of the child's admission to the ward to allow for initial fears and anxieties to also be considered so that first

[29] Manne SL, Lesanics D, Meyers P, Wollner N, Steinherz P, Redd W. Predictors of depressive symptomatology among parents of newly
diagnosed children with cancer. *Journal of Pediatric Psychology*, 1995;20(4): p.491-510
30 Sexson SB, Dingle AD. Medical problems that might present with academic difficulties. Child and Adolescent Psychiatric Clinics of North America, 1997; 6(3): p.509-522
31 Anderson, J. C., Williams, S. C., McGee, R., & Silva, P. A. (1987). DSM-III disorders in preadolescent children: Prevalence in a large sample from the general population. Archives of General Psychiatry, 44, 69-76.

level assistance can be provided to allay these fears and enable the child to adapt to the hospital environment more easily. In addition to identifying any pre-existing/ long-standing mental health issues (those related to the illness and those that are not), the screening will also enable speedy identification of a child's disclosure needs, thereby preventing exacerbation of anxieties and worries around illness and hospitalization.

E.2. Depth Assessments and Interventions

For those children identified with pre-existing/ long-standing mental health issues (those related to the illness and those that are not) in the screening process, depth assessments will be provided. These assessments will elicit details on the onset/ duration/nature of the child's problem, developmental history, family history and illness response. This holistic understanding of the child's issues will be used to design the requisite therapeutic interventions for the child and to provide family counselling.

The nature of interventions provided to the child may consists of: recognizing and acknowledging (accepting) the child's emotions, providing reassurance, framing the problem in such a way as to help the child gain insight/ understanding of the problem and its consequences, and suggesting to the child certain steps he/she can to reduce the problem. This last part depends on the problem—for instance, a child with anxiety may be taught relaxation exercises, or a child with anger issues may be taught anger management techniques. Play, art and storytelling methods will also be used to assist children with their problems. A critical part of working with these children would entail illness and disclosure issues—the NIMHANS team has already developed a few stories that will enable the disclosure process to occur i.e. for children to understand and make sense of their illness experience in simple and comprehensible ways.

E.3. Referral to Tertiary Mental Healthcare

While children with mild to moderate problems are assisted through direct intervention and inputs to the child and parent, others whose problems are more severe, thereby requiring psychiatric medication and/or in-depth therapeutic intervention (over a longer period of time) will be referred to the Dept. of Child & Adolescent Psychiatry, NIMHANS. Other than severity of the disorder, certain other criteria are considered for referral, such as the type of disorder and/or the context of the problem: children with post-traumatic stress disorder, self-harm issues, severe conduct symptoms that include violent behaviour would warrant depth assessments and longer term therapeutic work; also, children in extremely difficult family or social situations such as those with experiences of loss/grief/trauma, physical and sexual abuse may also be referred. Psychological testing required especially by children with intellectual disability and learning problems will also be undertaken at NIMHANS, including provision of disability certification (useful for school and for any government disability benefits the child is entitled to).

E.4. Group Sessions for Children

Group sessions for children between age 7 and 15 years, as and when they are available (given that they have various hospital treatment processes to undergo at different times in the day), may be conducted with a focus on life skills. UNICEF defines life skills as "psychosocial abilities for adaptive and positive behaviour that enable individuals to deal effectively with the demands and challenges of everyday life". There are a range of skills that relate to communication, assertiveness, problem-solving, conflict-management, coping with stress, managing inter-personal relationships and so on. While they are used more in the context of adolescent work, the NIMHANS Project team has adapted them to fit the needs of

younger children (who form the bulk of the children in the Kidwai ward). The module developed looks at common themes in children's lives—such as dealing with anger and anxiety, responding to bullying, maintaining friendships, staying motivated etc. These modules, in order to address cancer-affected children's lives and realities, could be contextualized for them i.e. address these children's emotional issues and help them cope in the context of chronic illness.

E.5. Parent Counselling

Given that parents' psychosocial well-being impacts the children's emotions and behaviours, sessions will be conducted for parents on management of emotional and behaviour problems, responding to developmental disabilities, and disclosure issues. Emotional issues will focus on helping parents understand children's anxieties and how to respond to them; behaviour management will focus on response to children's temper tantrums and demanding behaviours; and prevention and management of developmental disabilities will focus on enabling mothers to practice early stimulation methods in the hospital set-up and after.

3. Training and Capacity Building

3.1. Training for Integrated Child Protection Scheme (ICPS) Staff, Gujarat

The Gujarat State Child Protection Society (GSCPS) established in 2011, to implement child protection activities and schemes, with support from UNICEF, approached the Project for technical support and training of their ICPS staff. The objectives of the ICPS staff capacity building initiative are as follows:

- To enhance the quality of child protection and psychosocial care services available to vulnerable children.
- To provide special interventions to children living in difficult contexts.
- To enable and equip ICPS staff to deliver in-depth child protection and psychosocial care services.

The Project has agreed to assist Gujarat ICPS-UNICEF with their capacity building initiative over an 6 to 8 month period i.e. the training will include 3 components that will be delivered through 3 separate workshops of varying durations (10 days of training in all) and conducted over a period of 6-8 months.

In May 2016, the first of the three training workshops was implemented by the Project team (who served as the trainers) in Gandhinagar, Gujarat, for 35 ICPS staff. This 4 day workshop covered counseling techniques with children, how to approach and communicate with children, including first level and emergency responses to common child mental health issues and problems. The focus was strongly on developing practical skills. The specific training content included:

a) Understanding and practically applying child development concepts.
b) Identifying and understanding child psychosocial problems and contexts.
c) Acquiring skills in basic counseling/ communication techniques with children.
d) Working with 2 common/ critical trauma-related issues in children, namely i) loss/grief/death; ii) child sexual abuse.
e) (Based on the above) Learning how to conduct psychosocial assessments with children in difficult circumstances and accordingly, develop individual care plans.

The second level of training i.e. the next workshop will be implemented in the next quarterly period i.e. in August/ September 2016.

3.2. Mental Health Assessment for Children in Conflict with the Law, Centre for Child and the Law (CCL),National Law School of India University, Bangalore

The Project team was invited by the Juvenile Justice team of Centre for Child and the Law (CCL), National Law School of India University, Bangalore to conduct a session on "**Individual Psychosocial & Mental Health Assessment for Children in Conflict with the Law"** for 21 state appointed counsellors of Observation Home during the one day Workshop which was organized by the CCL team. The objectives of the workshop included:

1. To understand their challenges, concerns and needs, to revise the Handbook for counsellors working in Observation Home, based on this feedback.
2. To provide them some basic orientation of what the JJ Act 2015 provides for, in terms of Mental Health interventions for children in conflict with law.
3. Concerns related to the Draft JJ Model Rules 2016
4. Any other matter that enables effective service delivery to children in conflict with law

Based on the Project's work in the Observation Home, with children in conflict with the law, a mental health assessment proforma had been developed for use with this group of vulnerable children. The objectives of mental health assessment for children in conflict with the law are:

- To examine the (seriousness of) circumstances that the children come from and address the neglect/ abuse and trauma issues thereof.
- To identify children with psychiatric and/or personality issues and implement interventions accordingly.
- To ensure restorative and transformation processes which address accountability and encourage the under-taking of responsibility by understanding the impact of children's actions on victims/community and repairing harm.

The Project team shared the proforma they had developed with the counsellors of Observation Homes in the state. All participants were given a copy of the assessment proforma i.e. a Kannada translation was provided for their use. Each section of the assessment form was discussed in detail, with a focus on: i) the importance of each of the sections of the proforma in terms of what type of information it would yield--for example information collected about family such as economic status, living arrangements/parental relationships/ child's emotional relationship & attachment to parents/ illness & alcoholism in parents/ single-parenting will help us understand the child's vulnerabilities and also help to elicit family issues which might have contributed in the child's current issues.

; ii) the implications for intervention (from the information obtained)—for example, if peer influence has played a major role in the child's decisions about substance use and other risky behaviours, it implies that interventions need to focus on life skills such as assertiveness skills, refusal skills and coping with peer pressure; iii) how the questions should be asked of the child i.e. the tone, the language to be used etc.

At the end of the session, the facilitator also briefly discussed some of the first level responses that should be provided to children immediately following the assessment, to initiate the processes of transformation through insight facilitation, consensus building and motivation for change strategies. These first level inputs include: Future orientation (the impact of current behaviours on their future plans/ ambitions); examining consequences and

decision-making processes in behaviours such as stealing, violence and substance abuse and high risk sexual behaviours (pros and cons of actions)—impact on health, relationship with family and friends, on income/ economics; anger and anxiety management and control strategies; Conflict resolution strategies; empathy-building; frameworks for sexual decision-making.

Mental Health Assessment for Children in Conflict with the Law (Items in the Proforma)
- **Basic Information**(Name/ Age/ Place of Origin)
- **Presenting Problems/ Complaints** (emotional /behaviour problems including self-harm risk and physical aggression problems)- Self-Reporting Questions for Child
- **Reasons for current institutionalization** (circumstances of coming to the institution, incl. offence for which child is in institution- According to institution staff and police complaint)
- **Family History-** Family issues identified (living arrangements/parental relationships/ child's emotional relationship & attachment to parents/ illness & alcoholism in parents/ single-parenting…)
- **School History** (school attendance /Last grade attended/reasons for child not attending school, including drop out & school refusal)
- **Institutional History** (experiences & difficulties, circumstances of coming to the institution, incl. offence for which in institution)- According to institution staff and police complaint)
- **Peer Influence** (Time spent with peers/Which group of friends /Age of friends/ kind of activities or games played/Extent of influence of peers- in the context of school attendance/drug use/sexuality) **Trauma & Abuse** (physical, sexual & emotional Abuse experiences)
- **Substance Abuse** (type of substances used/ start & frequency of use/ craving/medical, legal impact of drug use)
- **Child's Perception of Problem** (Child's understanding of problem & why (s)he is in OH/ future plans to stay out of trouble/ skills to avoid conflict with the law/ motivation for change)
- **Cross-sectional Observations of Child** (cooperation/ social skills/ cognitive & thought process/activity levels/ time-place orientation/speech & language abilities)
- **Summary & Diagnosis** (Vulnerability, Pathology and Consequence)
- **Care plan** (Immediate interventions/ first level responses/ recommendations for further evaluation/ interventions).

3.3. Session on Children's Learning Problems, Centre for Child and Law, National Law School of India University, Bangalore

The project team was invited by the National Law School of India University, Bangalore, specifically the Centre for Child and the Law (CCL),that works on Right to Education (RTE), to deliver a session on "Academic Burden of Education System on Children". The session focused on the academic pressures and expectations that children today are constantly struggling with in their day to day life. The objective of this session was to question the rising trend of academics becoming a burden upon children where everyone around them- parents, friends, society, is expecting them to always excel.

The session was conducted in an interactive way. At the outset, participants were asked to do a small quiz where in each of the participants were given 3 levels of questions, to be completed within a time of 15 minutes. The 3 rounds were at increasing levels of difficulty-- wherein the 1st test was a simple (personal) 6 question test, the 2nd test was a general knowledge quiz with 20 questions and the 3rd quiz was a 35 questions quiz which had in-depth science and mathematics questions. The purpose of the quiz was to enable experiential understanding of academic stress/ burden and structure. The facilitators got the

participants to reflect upon their attitudes and expectations, which adults exert upon children and the need to support children with their challenges.

Moving further into the session, the facilitators provided insights into problems faced by children in the school system—and how the systems respond and deal with these. Three categories of student's groups – general majority students, students with privileges and students with difficulty, were identified. This was done to make the participants understand the common problems and issues that are faced by children belonging to these groups. The objective of this group division was to help participants understand:

- Learning is an inclusive process, that takes into account social, schooling, environmental, physical and mental factors.
- It is extremely important for teacher/parent to understand that each child is different and special and needs our support and assistance differently.
- For children falling in third category of student's group, learning problems may be attributed to one of the following factors namely – developmental disability, learning disorder and emotional/psychological problems.
- It is extremely important for teachers and parents to understand their child's behavioral and intellectual concerns adequately before deciding that they are a misfit to world of academics.

Common problems and concerns amongst teachers were also discussed including indiscipline, lack of motivation, inattention, irregularity, poor performance, naughtiness etc. were also discussed. However, if the teacher/parent needs to recognize the psychological problems that a child may be facing in order to help and assist the child.

To facilitate reflection on issues of academic pressures, focus was directed to the present education system. The characteristics of our present education system were discussed:How it focuses more on rote learning instead of appreciating knowledge and skilful learning. It is repetitive, burdensome, and stressful. Later, critical questions such as: 'What needs to change in our present education system?', 'How will such changes come about and who is responsible to bring in such changes?' were raised. Common responses from the participants were that our educational policies and government departments are apprehensive about making changes in present education system and therefore, no new developments take place in the education system. Several factors such as politics, corruption and tyranny also adds to the obstacles of bringing in educational reforms in the society. Finally, the discussion focussed on how small changes, to enable a child-friendly environment through appropriate learning materials, support system and changes in our attitude towards children could help in impacting the present education system. Instead of making children fear academics, including child/ learner-friendly objectives and appreciating children's concerns will help us in freeing them from unnecessary academic expectations.

The session was attended by 54 participants from various professional backgrounds, but mainly legal, educational, child services and developmental fields. They included college students, school students, teachers, NGOs members, CCL members, and people from disability institutions.

4. Material Development

Since there were summer vacations for most of this quarterly period and children in schools and child care institutions were largely unavailable, the Project was able to deliver a lower quantum of direct services. Instead, Project took the time and opportunity to develop and consolidate materials necessary for life skills and other sessions to begin again when schools and child care institutions re-open.

4.1. Life Skills Module for (Younger) Children

Previously, life skills modules on emotional development and relationship and sexuality for adolescents were developed and piloted in various child care institutions. Based on requests from child care institutions housing younger children, and the Project team's experience in these institutions, a life skills series focussing on issues relevant to younger children aged 8 to 12 years, has been developed. An initial draft comprising of 11 modules is ready for pilot. Themes include: identity, feelings, separation and loss, friendship and helpfulness, coping with anger, anxiety and worries, courage, bullying, conduct and motivation. The methods use a range of methods such as stories, art, films and board games. The objectives are to enable children to develop emotional regulation and inter-personal skills as well as to prevent them from developing conduct-related issues. The piloting of the module has already begun in 2 child care institutions.

4.2. Further Development of Relationship & Sexuality Life Skill Series for Adolescents

While the Relationship and Sexuality Life Skill Series for Adolescents was developed earlier on and already piloted with HIV infected institutionalized children, during this quarterly period, modifications and additions were made to this Series. Scripts were developed with 8 situations or contexts in which romance and sexuality plays out—such as a boy asking a girl to go home with him after a party, three adolescents convincing their friend that he 'needs to get' sexual experience, a girl pressuring a boy to run away with her and get married and so on. These scripts were converted into video clips with the help of a group of theatre artists volunteered to assist the team

4.3. Adaptation of Life Skills Series for Children with Disability

The Adolescent Life Skills Series on Emotional Development and on Romance and Sexuality, originally developed for children with normal sensory abilities, have been adapted by the Project team for children/ adolescents with disabilities, mainly those with visual impairment and those with speech and hearing disabilities. [Other materials will also be adapted for use with children with sensory disabilities over the project period].

4.4. Handbook for Teachers on School Mental Health

Based on the extensive mental health work done in government schools over the past two years, the Project has begun developing a handbook for teachers. This handbook focuses not only on providing teachers with an understanding of common child and adolescent mental health problems but also on providing them with first level responses to help them manage those problems which are at mild to moderate levels, in school. The section on externalizing disorders i.e. ADHD, conduct disorder, substance abuse, truancy and motivation issues, is complete. The section on internalizing disorders i.e. anxiety, depression, trauma and abuse is underway and will be completed in the coming months.

C. Operational Challenges

a) Follow Up on Permission for Observation Home Services

The Project team has continued efforts to obtain permission to provide services in the Observation Home. The matter was referred to the Chairperson of the Karnataka State Committee on Juvenile Justice. He referred the matter back to the magistrate who had withdrawn permission for the Project to work in the OH. Based on an understanding that this magistrate was no longer going to be serving in that position and that a new magistrate would take her place, it was hoped that an appeal could be made to the new person, to allow the Project to continue services in the Home. Repeated requests were made to the OH superintendent, DCPO and the ICPS Director (of DWCD) to arrange for a meeting with the new JJ magistrate; the Project is still awaiting DWCD's assistance in the matter.

b) Illustrators and Artists

Community initiatives, and in particular those that are for children often require a lot of information education communication (IEC) material. As described in this report and previous quarterly reports also, the Project has been actively developing materials. Much of this material development entails illustrations--for stories, picture cards and flip-charts for use with children and caregivers/ service providers. It has been difficult to find artists to produce these illustrations and when artists are found, there are some challenges with working with them: i) their costs are exceedingly high (for a budget such as this Project has); ii) it takes inordinate time and effort to work with them, through several drafts, to enable them to understand the objective of the illustrations and to therefore produce them accurately (as per the Project team's needs); iii) consequently, development of illustrated materials is long-drawn out and time-consuming process, which does not easily keep pace with the Project's work i.e. the illustrations are not ready in time for implementation of the program as per the Project's schedules/ life skills' session plans.

D. Plans for the Next Quarterly Period, July to September 2016

- (Re)obtain the necessary permissions and resume services for children in conflict with the law, in the Observation Home.
- Provide individual and group psychosocial services for cancer-affected children in the Kidwai Hospital.
- Continue remedial education pilot program in schools.
- Initiate services in the Government Home for Mentally Retarded Boys.
- Resume/ continue services in care and protection homes, including piloting of the Life Skills Series on Romance and Sexuality.
- Continue material development, including story illustration and development of other training and activity material for children and child care service providers.