



REPORT ON EXPERTS' MEETING
Psychosocial Care and support
of HIV-positive babies and
young children on ART
South Africa



education

Department:
Education
REPUBLIC OF SOUTH AFRICA



social development

Department:
Social Development
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Psychosocial care and support of HIV-positive babies and young children on ART held on 8 December 2005

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Parties Present:

- HSRC (website: www.hsrc.ac.za and www.hsrc.ac.za/research/programmes/CYFD/) represented by Linda Richter
- Hospice Palliative Care Association of South Africa (website: www.hospicepalliativecaresa.co.za) represented by Alani Alberts
- Cotlands (website: www.cotlands.co.za) represented by Stella Dubazana
- Wits Health Consortium (website: www.witshealth.co.za) represented by Joanne Potterton
- Children's Rights Centres (website: www.childrensrightscentre.co.za) represented by Cati Vawda and Noreen Ramsdam
- Department of Social Development (OVC Directorate) (website: <http://www.welfare.gov.za>) represented by Johanna de Beer
- Department of Social Development (ECD Focal Person) (website: <http://www.welfare.gov.za>) represented by Louise Erasmus
- Department of Education (www.education.gov.za) represented by Marie-Louise Samuels
- UNICEF (www.unicef.org) represented by André Viviers
- Independent – Nel de Vries-Gotink
- Absent with apology: Department of Health (website: www.doh.gov.za)

A CD with the presentations is available on request. Please send email with contact details to André Viviers at aviviers@unicef.org to request a copy of the CD.

Acronyms:

AIDS :	Acquired Immune Deficiency Syndrome
ART:	Anti-Retroviral Treatment
CABA:	Children Affected by AIDS
CRC:	Children Rights Centres
ECD:	Early Childhood Development
EPWP:	Expanded Public Works Programme
HCBC:	Home Community Based Care
HIV:	Human Immunodeficiency Virus
HSRC:	Human Science Research Council
MDI:	Mental Development Index
OVC:	Orphans and other children made vulnerable by HIV and AIDS
PDI:	Psychomotor Development Index
PEP:	Post Exposure Prophylaxes
PMTCT:	Prevention of Mother-to-Child Transmission
SANAC:	South African National Aids Council
UNICEF:	United Nations Children's Fund

Psychosocial care and support of HIV-positive babies and young children on ART

REPORT ON EXPERTS' MEETING

Psychosocial care and support of HIV-positive babies and young children on ART

Session Chairpersons:

- André Viviers (UNICEF – Project Officer: Early Childhood Development)
- Ms Marie- Louise Samuels (Department of Education/ Chairperson of the Inter-departmental Committee on Early Childhood Development)

Introduction

UNICEF, together with key government counterparts, organised a meeting with a few selected national experts on the psychosocial care and support of babies and young children within the context of HIV and AIDS. One of the critical aspects to be addressed by this meeting was the psycho-social care and support of babies and young children who are HIV-positive and on ART. This was deemed important as more and more babies and young children who are HIV-positive now have access to ART and this will prolong their lives and have a profound impact on them.

Very little is known at this stage about the physical impact of ART on babies and young children, and even less is known about the emotional and psychological impact of ARV treatment on young children (taken together with the effects of the HI virus on the brain and on the general development of the young child). Furthermore, there are other factors involved in the development and mental health of the child, such as poverty and other social conditions of the child and the family. The impact and outcome of ARV treatment has to be considered alongside all these other influences; hence the need to widen discussion and to explore possibilities in addressing these issues within the South African context.

This is a clear example of a situation where an integrated approach in responding to the survival and development of babies and young children is critical, and because policy is still being developed there is a good opportunity to advocate that psychosocial care and support are as important as the actual treatment with drugs; and to develop mechanisms within the health care and mental health systems that will facilitate this.

One of the first steps towards achieving this was to call a *Critical Meeting of Experts (10-15 people)* to discuss and explore this issue further and to crystallise

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concrete ideas to take forward with counterparts and partners.

This report provides an overview of the presentations, discussions and suggestions made at this meeting, which was held on 8 December 2005.

Welcome

Mr Viviers (session chair) welcomed all present at the meeting. He indicated that Ms Samuels (co-chairperson) was slightly delayed due to another commitment but would join the meeting soon.

Opening remarks: UNICEF Representative in South Africa: Mr Macharia Kamau

Mr Kamau indicated that it was estimated that 100 000 babies were either born HIV-positive or contracted HIV through mother-to-child transmission every year; of these, in the absence of any intervention or treatment, 50% die by the age of 2 and another 30% die by the age of 5. Thus, only about 20% of HIV-positive babies live beyond the age of 5 (though their life expectancy is still short). Currently, therefore, the majority of babies and young children living with HIV never reach school going age. The South African Government's *Comprehensive Plan for the Prevention, Care and Treatment of HIV and AIDS* will surely change this scenario significantly in the next few years. An integrated approach to treatment will save the lives of these children, and psychosocial care and support of babies and young children living with HIV will be an integral and important part of child survival and the quality of life they enjoy.

Mr Kamau also indicated that while most children born to HIV-positive mothers do not become infected, their chances for survival are diminished if the mother becomes ill with AIDS and dies. Many children born to HIV-positive caregivers spend their first years with ill and tired caregivers.

He emphasised that child survival and development are critical for UNICEF and that every effort is made to strengthen and support government's plans in this respect. That is why it was important to bring a small selection of experts and government counterparts together to open the discussion on the vital importance of psychosocial care and support of babies and young children as an integral part of treatment for HIV and AIDS, as children need to survive and thrive.

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Session 1

Sharing of knowledge, insights and experiences

The first session consisted of presentations by experts in the field, highlighting from different angles the importance of psychosocial care and support of children who are HIV-positive and receiving treatment. The sections below provide a summary of the PowerPoint presentations as well as an indication of the discussions that followed each presentation.

Improving the care of sick children in hospitals: Developing and testing psychosocial interventions. Prof Linda Richter, Human Science Research Council (HSRC)

Summary of Presentation

The focus of the presentation by Professor Richter was on a project aimed at improving the wellbeing of children admitted to hospital in the context of HIV/AIDS. The project tries to take cognisance of the following important contextual factors:

- a. HIV/AIDS has placed a tremendous burden on the health care system and affects the care provided to all children in hospitals and primary health care settings.
- b. Many children will be admitted to hospitals with chronic illnesses before qualifying for treatment, and the current care structures and practices within paediatric health care require attention.

The principles behind the project encourage thinking beyond children infected with and on treatment for HIV/AIDS. These principles assist in developing an approach which harnesses current opportunities. Specifically we are presented with important opportunities to do the following:

- We are presented with an opportunity to broaden our scope to vulnerable children in general and not to focus on orphans alone. A broader focus will harness better care for all children with chronic illnesses and disabilities, and improve primary health care provision for all these children, including HIV-positive children on ART.
- We have an opportunity to recognise the importance of involving people in their own solutions, and to include health care professionals and caregivers in the development of appropriate and realistic interventions rather than imposing

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“external expert” opinions.

The project came about when the group from the Child Youth Family and Social Development Research Programme at the Human Sciences Research Council were approached with a request to help improve the care of children in overburdened, stressful hospital conditions. The project worked within a participatory framework and engaged systemically with staff, caregivers and children in a regional hospital in Durban. The approach to interventions focused on working together with staff to avoid blame and to encourage staff and caregivers to create “their own” solutions. In preliminary workshops staff raised five specific areas of concern which they felt should receive priority. It was decided that the guiding principles in the approach to this project would be to focus on being action-oriented and solution-focused. Since the project had a larger goal of helping staff and caregivers in other care settings, it was decided that a good endpoint would be to develop training material, including videotapes, which could be used for wider distribution.

The process can be described as follows:

- a. Discussion meetings and video observations were used to describe conditions and problems facing paediatric care in the context of HIV/AIDS.
- b. Unobtrusive video observations were undertaken in the ward in order to observe naturally occurring events and to explore naturally occurring interventions. Video feedback was used to devise and discuss possible interventions
- c. Once possible interventions had been identified, they were to be tested and evaluated, and thereafter be included in training and dissemination at a broader level.

The staff priority concerns that were raised in the project included child distress and crying; assisting caregivers to cope with the hospitalisation of a child, and coping with worries the caregivers have about themselves and conditions at home; involving caregivers in painful procedures; active feeding; and preparation for returning home.

Professor Richter indicated that the larger goal of this project was to have segments of the five 20-minute training videotapes include some “real” live sections as well as some role-play sections, since the material would then appear more authentic to the viewing audience. The video plot and content would be scripted in a participatory manner, working with caregivers and staff, and would include their storytelling. The impact of these training materials would be evaluated and then

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distributed to other care centres.

Currently, progress in the project has seen the group collect over 40 hours of video observations over a period of 8 months. Some very good examples of naturally-occurring interventions have emerged, and both scripts and storytelling around the topics have been developed. The project is ready to begin with the production of videos and the filming of parts to be produced with actors.

Professor Richter showed demonstration videos on three of the topics: child distress and crying, indicating the importance of transitional objects (such as a face cloth); involving caregivers and children in painful procedures (infant massage); and active feeding, which is a high priority in diarrhoea and malnutrition units.

Crying and distress:

Crying is very distressing for children, staff and caregivers and while some crying is inevitable and healthy, children in hospital care environments are in pain, alone, and experience repeated separations from caregivers who visit them. All of this causes extensive distress with very little opportunity or support for regulation. The crying has a tremendous impact on the children themselves, and also on the caregivers and nursing staff, since crying elicits a physiological response and constant crying, as often seen in video observations, can be extremely stressful to care providers. One possible intervention which emerged was the use of transitional objects, which are important comfort objects that can help to bridge the gap in space and time between child and caregiver. A five minute video clip was presented as an example of an intervention which was observed in a ward and which occurred spontaneously. The summary of the video clip is outlined briefly:

During a visit to a toddler: the child's mother gently wipes him with a green cloth while she talks and plays with him. It is obvious that there is a strong caring bond between the two and he is able to be calm and engaged despite his illness. Once the mother leaves the child becomes very distressed and cries for over 10 minutes. As he moves around in the cot the child sees the green cloth where the mother left it, immediately one sees his recognition of the familiar object which carries his mother's smell and represents positive memories. He freezes, and then cries in protest for his mother, looking around for her. In her absence he retrieves the cloth and uses the cloth as comforter; returning to it again and again he engages in rhythmic movements with the cloth, tries to cover himself with it and refuses other distracters (such as a balloon). The nurse unwittingly puts the cloth away twice, not understanding the child's need and use for it, but once the assistant explains the significance of the cloth one sees the nurse gently wiping the child's face with the

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cloth and this brings some relief to the child.

Important points that emerged in the discussion of this type of intervention with hospital staff included the fact that objects needed to be comforting, but also needed to be chosen to reduce the risk of infection; dolls and soft toys were seen as inappropriate since they could carry infection easily and were difficult to clean and frequently stolen. Face cloths were considered appropriate as they were common, low cost and easily cleaned, but could still act as a comfort.

Painful procedures:

Painful procedures are inevitable and frequent in hospital settings under these circumstances. The condition of the child (such as being severely dehydrated) often makes normally straightforward procedures such as taking blood or putting up a drip extremely difficult and complex, and result in the child, staff and caregivers experiencing pain and distress. This level of distress can be alleviated by means of practical interventions which give some degree of control and active engagement with the procedure to the child and caregiver. An example of an intervention which emerged naturally in the observations of the ward was infant massage. Infant massage has long been used to assist medically fragile infants. Substantial research exists on its efficiency in assisting and providing relief to babies with addictions. Infant massage can alleviate pain and stimulates tactile and pressure receptors and can increase alertness. The summary of the video clip is outlined briefly:

A mother is attending to her child, who is very ill; his bottom is raw and the nappy changing is painful and distressing to the child. Knowing this, the mother rubs the child's arms gently to prepare and relax the child, then wipes his bottom gently and massages in circular repetitive movements. The child relaxes and engages in dialogue with the mother about the cream, at which point the mother invites the child to put cream on himself. The mother rubs the child's arms again and lets the child put on the cream and hold the container of the cream. The child applies the cream and gains some advocacy over his own illness. The mother then gently proceeds with changing the nappy; while the child protests she works calmly and the child appears to cope. Once the nappy has been changed the mother holds and comforts the child, acknowledging to him that this was a difficult and painful experience.

Discussions with staff indicated that this is a popular and culturally accepted intervention. After a demonstration by an infant massage trainer nurses felt that this could be a sustainable and practical skill which could benefit both staff and

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caregivers and could easily be transferred home when the child was discharged.

Active Feeding:

Active feeding is critical to children who are ill, particularly because of the common presentations of diarrhoea and malnutrition in the context of HIV/AIDS. Sick children do not feed easily, but survival and recovery is intrinsically linked to eating. Observations in the ward indicate that there is little attention to the facilitation of active feeding and the placing of emphasis on the social nature of feeding. It appears that there are deeply entrenched systemic barriers, including restrictive and rigid feeding times, and inappropriate food types and equipment. It is well known that children need to be actively fed and stimulated and children sometimes need considerable help in feeding, particularly when they are ill. The summary of the video clip is outlined briefly:

This part of the presentation covered a series of clips demonstrating the importance of active feeding and ways in which staff and caregivers can assist children to feed. The first clip demonstrates how difficult it is to feed a sick child and leads into a clip of a child sitting next to a sandwich, which she eventually falls asleep next to, to demonstrate the importance of active and supported feeding. The next three clips show a mother who has received feeding counselling supporting the child's neck and staying on the task in a gentle and responsive way; the same pair is shown when the child has recovered to demonstrate the social nature of the feeding interaction. The last clip demonstrates that children have special needs and a nurse is seen massaging a child's hand so that she able to eat independently despite severe spasms caused by malnutrition.

Important points were raised in discussion with staff, most importantly that a child alone will often not eat, although in hospitals children are often left to eat alone. Often inappropriate food types and dosages are given to sick children: it is known that small amounts should be given frequently and some foods are easier to feed a sick anorexic child than those often provided by external catering services. There are also often distractions during feeding which could be minimised.

Discussions:

Following the presentation by Professor Richter the following points were raised by the participants:

There are different ways in which this approach could be taken to scale, building from the micro-level to a larger outreach for the interventions shown here. It is

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important that the intuitive knowledge of parents and other primary caregivers be used as part of the strategies to strengthen parenting skills, as parents are the foundation of psychosocial care and support for their young children.

It was suggested that these skills and approaches should be utilised with Home Community Based Workers, as the psychosocial care and support of young children seems to be a particular skill that needs strengthening in HCBC (Home Community-based Care) work.

It was suggested that approaches and programmes such as this be shared with a broader network to promote low-cost/no-cost interventions that could make a difference in the lives of babies and young children. Of particular importance in this network would be relationships with the SABC and the print media.

It is important to follow a multi-pronged approach in dealing with children and caregivers in distress, and we should, as far as possible, try to include other children as well. It was important, too, to tap into the experiences of other community-based rehabilitation programmes.

The importance and use of volunteers should be carefully considered, as they could be either an asset or a burden to programmes.

The care of babies and young children who are HIV-positive. Ms Stella Dubazana, Cotlands

Summary Presentation

Stella Dubazana presented the following overview of the Cotlands Children's Hospice programme:

The hospice team created a homely and child-friendly environment for its young patients. Doctors and nurses did not wear uniforms and the décor was child-appropriate. Patients play with washable toys and enjoy age-appropriate children's programmes and videos on radio and TV.

Patients' relatives could visit at any time during the day, without a time restriction. This allowed the patients' mothers or primary caregivers to participate in routine procedures, such as washing and feeding their children.

The hospice team's first treatment action was to free children from pain by

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administering analgesics regularly and managing all other symptoms quickly and appropriately. Where patients were immobile, a comfortable space was prepared for them in the communal area of the hospice, allowing them to enjoy the company of the others. If this was not possible, a radio or TV was placed in the ward for entertainment. Wherever possible, patients were given toys that were hand-manipulated. Hospice staff made time to sit and talk to the patients or read books to them, allowing for important rest times. The team also harnessed alternative therapies like aromatherapy which have proved beneficial to patients' health and sense of wellbeing.

Staff ensured that no nonessential medical interventions or procedures were carried out, to avoid inflicting needless pain. Prior to medical procedures, staff explained to their patients what was going to be done, to make sure that the child was not taken by surprise. Analgesics were often administered after a painful procedure and patients were always given a great deal of reassurance, comfort and support.

It was deemed important to deal appropriately with changes in the physical appearance of young children. Cuddling and touching children despite their sometimes disturbing physical appearance made them feel loved. Questions were answered honestly and staff were vigilant in stopping teasing and mockery on the part of the other children.

A great deal of emphasis was placed on stimulation. Many patients cared for in the hospice came from traumatic backgrounds and lacked the initiative to get involved in activities going on around them. This might be because they had been ill, understimulated, depressed, abused or had simply forgotten how to play. In the stimulation programme, all play activities had a purpose. Through stimulation the caregiver was able to extend and develop patients' learning potential by guiding the play activities in a structured way. Caregivers tuned into the patients' needs in order to gain an understanding of their abilities and development.

Special activities such as outings were included in the stimulation programme to ensure that patients experienced regular changes of environment. Other activities included gross and fine motor activities, language development, social skills, balance, body awareness, cause and effect, classifying skills, concept development, coordination, counting concepts, creative expression, imagination, listening skills, problem solving, rhythm exploration, sensory exploration, size and shape discrimination and spatial awareness.

Not all play had equal benefits. Watching TV for hours was too passive to provide

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the mental and physical stimulation toddlers need. For stimulation to be meaningful, children needed social interaction, enthusiasm, variety and some degree of control. Children also needed partners who were sensitive to their cues and would provide encouragement and affection. “By stimulating children we create a healthy and challenging environment that will promote the child’s physical, mental, social and emotional growth”.

Cotlands undertook psychosocial assessment of each child, looking at factors such as personality and lifestyle, HIV history, adherence history, disclosure experiences of HIV status, relationships and support systems, attitude and socio-cultural context. The assessment also included areas of psychosocial stress such as the impact of HIV on parents, as stress brought about by the diagnosis of HIV infection presents a major crisis to parents. Individual support was important to maintain optimal psychological functioning, because decision-making is the key component in the early stages of HIV. In addition, factors that impacted on adherence, such as loss of financial support, lifestyle change, culture, emotions, physical and emotional setbacks, adjustment to treatment and stigmatisation and discrimination, also needed to be taken into consideration.

Some experiences of HIV-positive children on ART entering the education system were also highlighted. These included:

- The effects of HIV and AIDS on the brain, causing developmental and cognitive delays, significantly impacts on the entering into the school system.
- The critical issue of stigma, particularly in regard to taking medication during school hours.
- Frequent absenteeism as a result of medical care requirements e.g. regular hospital or clinic check-ups.
- Disclosure of their condition and associated issues, including confidentiality.
- The need for support during the school day.
- Awareness of restrictions associated with school excursions and trips.

Discussions:

Following Ms Dubazana’s presentation, it was emphasised that ART for babies and young children should start as soon as possible to ensure the best possible outcomes for young children who are living with HIV.

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Neurodevelopment status and parenting stress of HIV-infected children and their caregivers in Soweto, South Africa. Ms Joanne Potterton, University of Witwatersrand.

Summary of Presentation

Ms Potterton in her presentation highlighted the following:

The central nervous system is among the most frequent and serious targets of HIV (Simpson *et al.* 1996), and neurological complications have been described in HIV infected children since the early 1980s (Epstein *et al.*, 1985; Belman *et al.*, 1986). HIV encephalopathy may present as a sub-acute progressive, plateau or static course (Ultman *et al.*, 1985). Developmental delay may be the first clinical sign of HIV infection in children. (Belman *et al.*, 1990). The prevalence of neurodevelopment delay has been reported to be 30%-40% and cognitive, motor and speech delays have been described (Gay *et al.*, 1995; Smith *et al.*, 2000; Wolters *et al.*, 1995). Parenting stress has been found to be increased in caregivers of HIV-infected children (Linsk & Mason, 2004) and the biological mothers of HIV-infected children are particularly vulnerable (Linsk & Mason, 2004). It was found that high parenting stress levels may impact negatively on child development

Ms Potterton highlighted the fact that the hospital use the Bayley Scales of Infant Development II one of the most widely used developmental assessment tool in paediatric research. Scores are obtained in the following three areas: cognitive; motor and behavioural and the raw scores are then converted into standard scores: the Mental Developmental Index (MDI) and the Psychomotor Developmental Index (PDI). Validity and reliability have been well established on a number of study samples. Further and complementary to this they also use the Parenting Stress Index (Short Form), which contains 36 items across three subscales: parental distress, parent-child dysfunctional interaction and difficult child, and is scored on a 5 point scale. This scale has been shown to be valid and reliable and official translations into Zulu and Sotho have been accepted and showed good test-retest reliability when piloted.

The preliminary results showed that 74% of caregivers have scores of 90 or more on the PSI-SF. These scores indicate clinically significant levels of parenting stress. On the Bayley Scales of Infant Development II, analysis of facet scores revealed that 77.5% of children had delayed gross motor skills and 82.5% of children had delayed speech and language development.

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Ms Potterton presented the following Case Study, which indicates that developmental delay is significant and could be attributed to a number of factors. These include HIV encephalopathy, muscle weakness, malnutrition and poverty. It also indicates that parenting stress levels are clinically significant and warrant further investigation.

Age (months)	Ht	Wt	ART	CD4	MDI	PDI
19	77cm	10.6kg	no	10.9%	55	<50
22	78cm	10.9kg	start			
25	83cm	11.8kg	yes		72	72
28	85cm	12kg	yes			
31	87cm	12.6kg	yes	29%	79	87

In conclusion, Ms Potterton remarked that developmental delay is a significant problem in HIV-infected children in Soweto, South Africa. One should also understand this within the context of the high levels of poverty that exist in families affected by HIV. Further, parenting stress levels are high in caregivers of HIV-infected children. These findings support the need for a multidisciplinary, family-centred approach to the long-term management of HIV-infected children.

Discussions:

Following Ms Potterton's presentation, the following key comments were raised by the participants:

It is important to take into account the impact that poverty and malnutrition had on the young child, and how this, combined with HIV, may worsen the outcomes for the young children.

The parent's/primary caregiver's psychosocial wellbeing plays an important role in the wellness and level of psychosocial support and care that a baby and young child receive. Therefore it is critical to provide a package of support to both the

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parent/caregiver and the child.

Concern was raised that in many instances there was too long a waiting period before treatment was started with babies and young children. In many instances treatment was only started when the child was ill and by then the HI-virus had already done irreversible damage, especially if the impact that HIV has on the brain is taken into account.

Psychosocial issues in the Paediatric ART Programmes. Ms Alani Alberts, Regional Mentor of the Hospice Palliative Care Association of South Africa.

Summary of Presentation

Ms Alberts indicated that the aims of ART are:

- to suppress viral replication – ART does NOT eradicate the virus;
- to allow regeneration of immune system;
- to prevent opportunistic infections;
- to alter/reverse the course of existing opportunistic infections;
- to decrease hospitalisations;
- to increase survival;
- to improve quality of life;
- to restore hope in patients, family members and health care providers; and
- to possibly reduce HIV transmission.

She emphasised that for ART to be successful, adherence was of the utmost importance as poor adherence leads to drug resistance. This is important to note as there are only two treatment regimes at the moment and the expected affectivity range per regime is \pm five years.

Ms Alberts presented four case studies on the impact of ART and psychosocial support on young children. She indicated that the following psychosocial criteria for children to start on ART applied in their programmes:

- **Mandatory:** At least one identifiable caregiver who is able to supervise the child or administer medication (all efforts should be made to ensure that the social circumstances of vulnerable children, e.g. orphans, be addressed so that they, too, can receive treatment).
- Disclosure to another adult living in the same house is encouraged so that there is someone else who can assist with the child's ART.

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The following challenges to adherence with children were noted:

- Developmental level of the child
- Complexity of the therapy
- Refusal to take medication
- Dependence on the caregiver
- Side effects of the therapy
- No visible benefit seen by patient/family
- Timing of doses
- Remembering appointments

Ms Alberts highlighted the predicament between the policies of not institutionalising children vs. the greater effectiveness of ART in, for example, foster care, child headed households etc.

The following were some aspects regarding the quality of life for children on ART that needed to be taken into consideration as part of the psychosocial care and support:

- Medication for the rest of the child's life
- Children's rights (decision making)
- Quality of life considering other symptoms
- Preservation of the whole family
- Availability of food and other resources

One of the ethical issues that she raised is whether we should prolong life just because we can. This is especially the case if the child did not make the decision and depended on an adult, who might have ulterior motives (grants), to make the decision. The answer remains YES!

Discussions:

One of the key comments that followed Ms Alberts presentation was that the quality of life of the child while on treatment is of the utmost importance and contributes to the general as well as the psychosocial wellness of the child.

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Children's rights to psychosocial care as essential in the treatment of HIV and AIDS. Ms Cati Vawda, Children Rights Centre

Summary of Presentation

The CRC's premise in HIV/AIDS work was that Children's Rights are essential from start to finish because they provide a comprehensive, integrated and holistic approach and link policy and practice. HIV and AIDS caused all rights to be violated and the promotion of rights limited the spread and reduced the harmful effects of HIV and AIDS.

Ms Vawda indicated that children and their caregivers need supportive networks as no child can be raised effectively in isolation, by only one adult, and caregivers needed assistance with caregiving; economic and material support; advice, and social, psychological and emotional support. These networks need to include and coordinate civil society and government.

She indicated that the CRC's focal points on HIV and Children are:

- Promoting Children's Rights for Children in Especially Difficult Circumstances – OVC/CABA
- The Treatment and Prevention Triangle where one intervention supports the other
- Linking Treatment, Prevention and OVC/CABA issues, processes and people

HIV/AIDS-specific work done by the CRC included:

- OVC/CABA
- Prevention – Life skills, Play, Child Rights Education, Condoms, PMTCT+, PEP
- Treatment
- Networking
 - Coalition
 - KZNHACSN
 - SANAC Children's Sector
 - Strategic partners and processes
- Information Services
 - Testing Activity Booklet
 - Community Help Booklet
 - Caregivers Booklet
 - Butterfly Storybook

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HIV/AIDS is also integrated into all other programmes of the CRC, which include:

- Capacity Building
- Child Participation
- Play Rights
- Monitoring
- Social Security
- Children in Especially Difficult Circumstances
- Information Services
- Newsletters
- Website
- Briefings
- Help Desk

Ms Vawda also emphasised the following actions related to orphanhood:

- Ensure quality, stable care for children
- Delay orphanhood – keep parents alive and well
- Prevent increased levels of orphanhood:
 - Prevent new infections
 - Reduce mortality from existing infections

She emphasised the relationship between Treatment and Orphaning and highlighted the fact that treatment is the only intervention to delay orphanhood. She also indicated that treatment causes an improvement in the quality of parenting through reduced morbidity. She indicated that to fulfil adults' right to health care, you should protect children's rights to family care; adequate standard of living; education; play; and protection from harm

Ms Vawda pointed out that the emerging message was clear - treatment works better if started earlier. She further indicated that it needs to be remembered that when we deal with children and HIV/AIDS:

- it is difficult to diagnose young children clinically and there is a need for tests;
- children get sicker, faster than adults;
- children die earlier than adults;
- the illness of a young child is hard on the mother and other children;
- Early testing is vital for the start of treatment.

She stressed the importance of expanding and strengthening integrated, holistic approaches to prevention, treatment and impact mitigation, as well as the scaling up of testing and treatment, which includes PMTCT Plus and PEP, and early identification of children at risk within adult-focused programmes, including Home-based Care, TB and STI programmes.

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The following were listed as important advocacy points for prevention:

- PMTCT and PMTCT Plus
 - All positive tests should be followed by CD4 counts
 - Testing should begin prior to pregnancy or early in pregnancy
 - Support groups should start prior to delivery
 - Condoms and Reproductive Health Services should be in place for 12-year-olds and up;
- Improvement of HBC practices;
- Recognition of play and recreation as purposeful activities;
- Forming stable relationships of trust with adults who care and listen; and
- Having role models for girls and boys.

Ms Vawda highlighted the fact that fear of treatment should be dealt with, and suggested the following:

- Demystify treatment;
- Simplify guidelines;
- Educate and support caregivers as well as health care workers
- Integrate children's treatment literacy into general treatment literacy ;
- Support networks of health care workers; and
- Ensure coordination and communication between health workers and community workers.

Ms Vawda also emphasised that efforts should be made to “Get Tests Right for Children” by ensuring the availability of tests that were cheaper, simpler and easier to administer, and by ensuring that there were shorter turn-around times. She indicated that dried blood spots for PCR are a good example.

It is also important to get medicines right for children to ensure:

- fixed dose combinations and simpler formulations;
- reliable drug supply of paediatric medicines; and
- appropriate paediatric ARV formulations, such as liquids for infants smaller than 10-12kg and solid drugs for older children.

It is also important that medicine is affordable and that paediatric drug prices are monitored. Further, a wider range of drugs must be made available.

She emphasised that in ART for young children the country should strive for Young Child-Friendly Health Services to include the following:

- Linking of home – clinic – hospital – school (and ECD sites)

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- Support and improvement of parenting and child development as a foundation in service delivery
- Consideration of other socio-economic factors (caregivers, poverty, abuse-neglect-exploitation, children without caregivers)
- Training of all Health Care Workers in holistic HIV treatment
- Service provider support networks
- Pain management
- Encouraging children to be partners in their own health care
- Disclosure to children of their health status
- Establishing ethical guidelines to ensure the child's right to privacy when children's own stories and images were to be used publicly

The CRC is doing the following with regard to Children and HIV/AIDS

- Linking Treatment – Prevention – OVC/CABA
- Challenging prevention messages and strategies, and promoting testing, treatment literacy and access to treatment
- Improving treatment
 - Monitoring ART roll-out
 - Advocacy on specific issues
 - Treatment literacy
 - Treatment and testing materials
- PLUS promoting comprehensive social development
- Promoting play rights in safe spaces and in all facilities and services
- Encouraging adults to listen to children beyond participation rhetoric
- Linking comprehensive social security to treatment
- Supporting identity, education, grants, food and nutrition support
- Giving strong and effective referrals including psychosocial support

Ms Vawda informed the meeting of the Concerned Paediatricians Meeting with NDOH, saying that they formed task teams to draft recommendations on (a) Testing and Early Diagnosis; (b) Training and Guidelines; (c) Integration and Quality of Services; (c) Pharmacology; (d) PMTCT; and (e) Adolescent Health. What is missing in this group and the deliberations, however, are social workers, psychosocial support practitioners, educators, Home Based Care Workers, and specialists in children with disabilities, amongst others.

She emphasised the importance of SANAC being able to work effectively as the Country Coordinating mechanism on HIV and AIDS. It was noted that the Children's Sector is represented on SANAC and that the Children's Sector Network is coordinating within the sector and with other non-governmental representatives. In

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conclusion, Ms Vawda emphasised that treatment should include drugs, services and loving care, and that prevention, testing and treatment are all part of the same package. We must make the ARV Roll-Out work for Children! Leave no child behind!

Discussions:

Following Ms Vawda's presentation, the participants emphasised the importance of an integrated approach to addressing the rights and needs of babies and young children living with HIV.

An introduction to print media/books that deal with the psychosocial care of sick children. Mr André Viviers, UNICEF South Africa

Mr. Viviers provided the meeting with an overview of the role media could play in providing tools for parents and young children on psychosocial support and care. He tabled the following two books as examples:

- **The Little Hare (*Umvumdlana*)** is a book that tells the story of a little hare who does not feel well. It deals with the feelings that the little hare experiences in a concrete and understandable manner for the young child (birth to three) and also suggests simple no-cost activities that caregivers and family members can do to make children who do not feel well feel better. This little book not only explains the feelings and possible support to be provided in an enchanting and young child-friendly manner, but also provides key suggestions to caregivers to enhance the psychosocial care and support of young children who are sick and/or not feeling well.
- **Look Who Loves You! (*Bheka ukuthi ngubani okuthandayo!*)** is a book for young children (birth to three) dealing with death in the family. It is written in a rhythmic manner using phrases from a traditional lullaby indicating to a young child how her family loves and cares for her, despite the fact that her mother passed away. It includes extended family members and each picture depicts an important support and care-giving activity for the young child. The layout of each page is done in such a manner that it can facilitate interaction between the young child and the caregiver who reads the book to her/him. It has little pictures to show the child and expand his/her vocabulary or to play little "what is this?" games. This book can be used very effectively in providing psychosocial care and support to a young child who has lost a family member.

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Session 2

Critical interventions needed

Participants in the meeting put forward the following suggestions as critical interventions for the psychosocial care and support of HIV-positive babies and young children on ART. These are divided into 4 broad categories as indicated below:

The system/services

- Ways should be found to use model programmes and interventions for learning and demonstrating critical interventions. This can have a replication effect to improve the whole system for the treatment, care and support of young children living with HIV.
- It is important that these discussions feed into the *National Integrated Plan for Early Childhood Development* as the government vehicle to ensure the survival, protection and development of babies and young children.
- Children, no matter how young, should be seen as partners in their own health care and treatment.
- The psychosocial care and support of babies and young children should be focused more widely than just on HIV, within the context of poverty and inequality.
- It is important that the health and social service system be strengthened at a practical level to facilitate the implementation of policies and to make them work for children.
- Coordination, collaboration and partnerships between government and civil society are of critical importance in the treatment, care and support of children living with HIV.
- Ways should be sought to expand the EPWP into the process of psychosocial care and support for babies, young children and their families.
- Programmes and interventions at antenatal clinics and other health care facilities are important for ensuring that psychosocial care and support is introduced from the start.
- Nodes of care and support for babies and young children and their families should be supported (and developed where they do not exist) as they form important entry points for primary caregivers. This would also provide safe spaces for young children.
- Linking with existing processes and structures is important so as to avoid

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duplication and “reinvention” of approaches and processes. Thus it is important that information be shared and role-players be kept in the loop of developments.

- It is important that the health system; education system and social service system be prepared to deal with babies and young children who live with HIV (and who are on ART) in a comprehensive, sensitive and integrated manner.
- Central to all the interventions should be the rights of children (babies and young children) as this is one framework that will ensure that psychosocial care and support will be introduced together with other interventions.
- The training of health care, social service and education professionals in how to deal with the impact of HIV on babies and young children is of paramount importance.

Household/family interventions

- The importance of play in the development and psychosocial care and support of babies and young children must be recognised.
- It is important to recognise that HIV is a “family disease” and there should be a family rather than an individual approach.
- HCB Caregivers should be seen and developed as important service providers in the treatment and psychosocial care and support of babies and young children at a household level.
- It is important to support and strengthen parenting capacity development at a community level so as to facilitate psychosocial care and support for babies and children at a household level.
- Child heads-of-households and grandparent heads-of-households and other primary caregivers should be given psychosocial care and support, as many of these persons have to deal with babies and young children in the midst of their own trauma and difficult situations.
- It should be seen that the whole system for the care, protection and development of young children (0-4) needs to be transformed.
- Programmes should include adolescent parents.

Resources/communication

- The power and importance of the media in South Africa should be recognised and used to promote psychosocial care and support of families and children, particularly young children affected and infected by HIV and AIDS. There should be clear and caregiver-friendly messages on the psychosocial needs of babies and young children.

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- It is important to make sure that the information reaches “the people”, but care must also be taken to avoid information overload. It is important that information be provided as needed at different times and through different approaches. Messages should be coherent and not cause confusion.

Research needs to be undertaken on the following:

- The effects of trauma on babies and young children (e.g. death in the family);
- The effects of ART on babies and young children;
- The problems that children living with HIV might encounter when entering school;
- Integrating the role of health care practitioners and other professionals in the psychosocial care and support of young children as part of the ART package; and
- How best to support parents and other primary caregivers in providing psychosocial care to their young children as an essential ingredient for child survival.
- There is a need for a clearing house on information pertaining to the topic of babies and young children living with HIV, and treatment.

Way forward

The following key actions were agreed upon together with the aforementioned:

- The report of the “Experts’ Meeting” will be finalised and distributed, together with copies of the presentations and other relevant information.
- The outcomes of this meeting should be used to impact on future agendas for action and advocacy for the promotion of psychosocial care and support as an equal component with ARVs for babies and young children.
- The groups who met today should be seen as a resource and meet regularly. There was a need for another meeting early in 2006 (Q1)
- Attention should be given to the needs of young children living with HIV in terms of their entering into the education system and there is a need for an integrated approach.
- The discussion on ART, HIV and young children should be more strongly introduced into the ECD sector.
- It is important to grow and sustain the momentum that this meeting has started.
- It was suggested that this group link with the Concerned Paediatricians Group.

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