Psychosocial Support for Children with Disability and their Carers

Discussion Paper

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ABBREVIATIONS AND ACRONYMS

ACRWC  African Charter on the Rights and Welfare of the Child
AIDS   Acquired immune-deficiency syndrome
ARI    Acute Respiratory Infection
ART    Antiretroviral Treatment
CBR    Community-based rehabilitation
CRC    Convention on the Rights of the Child
CRPD   Convention on the Rights of Persons with Disabilities
DHS    Demographic Health Survey
ESA    Eastern and Southern Africa
HBC    Home-based care
HIV    Human immunodeficiency virus
HIVAN  HIV acquired Nephropathy
HLM    High level meeting (UN)
ICF    International Classification of Function, Disability and Health
IPP    Invasive pneumococcal disease
OVC    Orphans and other vulnerable children
OVCY   Orphans and other vulnerable children and youth
PSS    Psychosocial support
REPS SI Regional Psychosocial Support Initiative
RIATT  Regional Inter-Agency Task Team (on children and AIDS)
SADC   Southern African Development Community
UN     United Nations
UNGASS United Nations General Assembly Special Session on HIV and AIDS
UNICEF United Nations Children’s Fund
WHO    World Health Organisation
## DEFINITION OF TERMS

<table>
<thead>
<tr>
<th>Terms</th>
<th>Definition (adapted from SADC PSS Framework, p. 9-11)</th>
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<tr>
<td>Caregiver</td>
<td>A caregiver is any person giving care to a child in the home environment. Primary caregiver is the main person who lives with a child and provides regular parenting care for the child in a home environment. This often includes family members, such as parents, foster parents, legal guardians, siblings, uncles, aunts and grandparents or close family friends. Secondary caregivers include community members and professionals such as nurses, teachers or play centre minders who interact with a child in the community or visit a child at home but do not necessarily live with the child. Child and youth caregivers include children and youth who are caring for other children, ill parents and relatives and/or heading households (SADC, 2010).</td>
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<td>Community-based Rehabilitation (CBR)</td>
<td>CBR focuses on enhancing the quality of life for people with disabilities and their families, meeting basic needs and ensuring inclusion and participation. It has been developed for resource poor settings and includes interventions for education, health, access to work and poverty alleviation (etc. <a href="http://www.who.int/disabilities/cbr/en/">http://www.who.int/disabilities/cbr/en/</a>)</td>
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<td>Child</td>
<td>Any person younger than 18 years (SADC, 2010).</td>
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<td>Child with disability</td>
<td>A child who has a disability.</td>
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<td>Comprehensive Response</td>
<td>An intervention or effort that meets the complete set of basic needs or defined minimum standards across multiple services that addresses the survival, development, protection and participation rights of children and youth while addressing vulnerability (SADC, 2010).</td>
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<td>Counselling</td>
<td>“Counselling is talking to a counsellor about your situation and your problems and worries. The counsellor will help you make plans and decisions, give you information and help you find answers to your questions. Counselling is not about telling you what to do; it is about helping you decide what you think is best to do and giving you support for following your decisions through.” Counselling may take place in a one-to-one situation or in groups and may be facilitated by a professional or lay counsellor (SADC, 2010).</td>
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<td>Chronic illness</td>
<td>Any disorder that persists over a long period and affects physical, emotional, intellectual, vocational, social, or spiritual functioning</td>
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<td>Deprived</td>
<td>A situation in which the basic survival, development, protection and participation needs and rights of a person (including children and youth) have not been met (SADC, 2010).</td>
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<td><strong>Disability</strong></td>
<td>Disability is a complex phenomenon which “results from the intersection between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis” (United Nations, 2008). It is also an umbrella term covering three levels of disability 1) changes in body structure or functioning such as social, mental, intellectual, sensory and physical impairments that may lead to 2) activity limitations and/or 3) participation restrictions. An ‘impairment’ is a problem in body function or structure; an ‘activity limitation’ is a difficulty encountered by an individual in executing a task or action; while a ‘participation restriction’ is a problem experienced by an individual in involvement in life situations.</td>
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<td><strong>Family</strong></td>
<td>A social unit created by blood, marriage, adoption or defined by a common line of kinship or relationship of a paternal or maternal nature. This can be biological or adoptive. It can be described as nuclear (parents and children) or extended (the conjugal family as well as encompassing other relatives or descendants of the husband and/or wife) (SADC, 2010).</td>
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<td><strong>HIV-related disability</strong></td>
<td>Disability that was acquired as a result of HIV, its opportunistic infections or its treatment. HIV-associated conditions affecting all body systems (mental, physical and sensory) which have the potential to translate into activity limitations and participation restrictions. In a wide sense, HIV-related stigma can lead to participation restriction as well and could also be regarded as disability.</td>
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<td><strong>Household</strong></td>
<td>A social unit of people (not necessarily related by blood or marriage) living together in the same house or compound, usually sharing the same food or cooking facilities (SADC, 2010).</td>
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<td><strong>Life skills</strong></td>
<td>Psychosocial, interpersonal and self-management skills that help people make informed decisions, communicate effectively and cope with adversity (SADC, 2010).</td>
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| **Mental health** | Mental health is a state of wellbeing in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (WHO, 2009). Mental health forms the basis of our thinking and communication skills, learning, emotional growth, resilience and self-esteem (The Regents of University of Michigan, 2009). When the individual is mentally healthy he/she will:  
  - form positive relationships  
  - cope with stress and adversity  
  - thrive  
  - adapt |
<p>| <strong>Morbidity</strong> | Departure from a state of physical or psychological wellbeing, resulting from disease, illness, injury, or sickness. |</p>
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<td>Mortality ratio</td>
<td>The ratio of deaths in an area to the population of that area; expressed per 1000 per year</td>
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<td>Orphan</td>
<td>A child aged 0–17 years whose mother (maternal orphans) or father (paternal orphans) or both (double orphans) are dead. The term ‘social orphan’ may be used to describe children whose parents are alive but who are neglected or abandoned by their parents or whose parents are no longer fulfilling any of their parental duties (SADC, 2010).</td>
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<td>Person with disability (People with disabilities, PWD)</td>
<td>Persons with disabilities “include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2008).</td>
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| Psychosocial                            | Psychosocial represents the relationship between the psychological and social aspects of our lives, with each continually influencing and interacting with the other. Every person is influenced by the interaction between:  
  • the psychological, or intra personal components which are the cognitive, emotional and spiritual aspects of our lives and  
  • the social, or the inter personal relationships with family, community and friends as well as the broader social environment such as culture, traditions, religion, socio-economic and socio-political environment. |
| Psychosocial support                    | Psychosocial support is a continuum of love, care and protection that enhances the cognitive, emotional and spiritual wellbeing of a person and strengthens their social and cultural connectedness. Effective psychosocial support enhances individual, family and community wellbeing and positively influences both the individual and the social environment in which people live. |
| Psychosocial wellbeing                  | Psychosocial wellbeing is the state in which individuals, families, or communities have cognitive, emotional, and spiritual strengths combined with positive social relationships. This state of well being motivates the development of life skills which enables them to understand and engage with their environment, and make healthy choices which leads to hope for the future. |
| Rehabilitation                          | Rehabilitation is a treatment or treatments designed to facilitate the process of recovery from injury, illness, disease, impairment or disability to as normal a condition as possible (http://medical-dictionary.thefreedictionary.com/rehabilitation). |
| Risk                                    | The possibility, chance or threat that one will be deprived or exposed to a phenomenon with negative consequences in the immediate, medium or long term (SADC, 2010). |
| Social protection                       | All public and private initiatives that provide income or consumption transfers to the poor, protect the vulnerable against livelihood risks and/or enhance the social status and rights of the marginalized, with the objective of reducing the economic and social vulnerability of poor, vulnerable and marginalized groups (SADC, 2010). |
| **Sustainability** | Ensuring that human development efforts achieve lasting improvement on the lives of children, youth and their families/carers and communities without bringing about any harm or compromising their wellbeing and that of others in the present or the future (SADC, 2010). |
| **Vulnerability** | A state of high risk of deprivation or, according to the World Bank, “an expected welfare loss above a socially accepted norm, which results from risky or uncertain events and the lack of appropriate risk-management instruments” (SADC, 2010). |
| **Vulnerable children** | Children who are unable or who have diminished capacity to access their basic needs and rights to survival, development, protection and participation as a result of their physical condition or social, cultural, economic or political circumstances and environment and require external support because their immediate care and support system can no longer cope (SADC, 2010). |
| **Vulnerable households** | Households that are unable or that have diminished capacity to access the basic needs and rights of their members (SADC, 2010). |
| **Youth** | The SADC framework defines youth as persons aged 18–24 years. It recognizes that the period of transition from childhood to adulthood places young people at greatest risk of deprivation of basic needs and rights. UNICEF and the World Health Organization define youth as every person between the ages of 15 and 24 years and young person as aged between 10 and 24 years; and the African Youth Charter defines youth or young person as aged between 15 and 35 years (SADC, 2010). |
INTRODUCTION

Children with disabilities and their caregivers are particularly vulnerable to stress (WHO, 2011; Freeman, 2006; Dickman & Roux, 2005; Groce, 2004; Yeo, 2001; Neubert & Cloerkes, 1994). Their stress levels might be higher if a person with more severe disabilities is living in the household. There is evidence to indicate that up to 70% of mothers and 40% of fathers of severely disabled children have been found to be distressed (Sloper & Turner, 1993). Parental distress and family functioning impacts on children’s psychosocial wellbeing in numerous ways and affects their cognitive, behavioural and social development. In addition, environmental and social barriers to participation in society increase the social vulnerability of families and children with disabilities. Psychosocial support (PSS) aims to address psychosocial wellbeing of children in general. However some children are more vulnerable than others and programmes to support vulnerable children need to take this into consideration through mainstreaming disability as well as through providing disability specific or adapted interventions. Psychosocial support should also be mainstreamed into programmes to support children with disabilities and their families.

This paper will discuss PSS and disability in five sub-chapters. The first chapter will provide an overview of the regional PSS approach, common disability concepts and a short situation analysis of children with disabilities. The second section will then discuss the interrelationship of disability and HIV and highlight three areas relevant to children 1) children with disability and their vulnerability to HIV, 2) children living with HIV and their risk of developing disabilities and 3) issues around increased care giving burden, HIV and disability. The section thereafter (third chapter) integrates disability within the current PSS approach in order to provide suggestions on how to address the issues raised in chapters one and two. The last two chapters go beyond this point and provide suggestions on how to mainstream disability within programmes (chapter four). The last chapter (five) identifies gaps within the current literature and research. This chapter also identifies opportunities for capacity building, intervention development and advocacy.

Understanding psychosocial interventions

According to SADC (2010), the term psychosocial is used to describe, “...the close connection between psychological aspects of our experience (that is, our thoughts and emotions) and our wider social experience (that is, our relationships, practices, traditions and culture). It also takes into account the physical and spiritual dimensions (value systems, beliefs and self-awareness) of an individual” Psychosocial pertains to the interplay of an individual’s intrinsic factors and the extrinsic factors acting upon that individual (2010). To extend on this, REPPSI defines psychosocial wellbeing as:
“the state in which individuals, families, or communities have cognitive, emotional, and spiritual strengths combined with positive social relationships. This state of well being motivates the development of life skills which enables them to understand and engage with their environment, and make healthy choices which leads to hope for the future.”

Thus their wellbeing is shaped by the interplay of intrinsic and extrinsic factors acting upon an individual — that is all things psychosocial. Psychosocial wellbeing is influenced by the continuous care and support a person receives from their family, community or organizations, that is, their psychosocial support (ibid.). The SADC framework lists three main domains of PSS: 1) skills and knowledge support, 2) emotional and spiritual wellbeing and 3) social wellbeing (see table 2)

Table 1: Domains of psychosocial support services *(SADC, 2010)*

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<th>Psychosocial domain</th>
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<td>Skills and knowledge (cognitive)</td>
<td>Skills and knowledge lead to competencies and capacities to cope with life’s demands and stresses and to manage relationships well. This includes problem solving, planning and decision making, stress management, negotiation, assertiveness, using culturally appropriate coping mechanisms, and ability to assess strengths in relation to needs.</td>
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<td>Emotional and spiritual wellbeing (intrapersonal)</td>
<td>Emotional wellbeing is an individual’s capacity to live a full and creative life and the flexibility to deal with life’s inevitable challenges. The intrapersonal area concerns the individual’s ability to know and to manage him or herself. It determines how in touch with his or her feelings a person is, how a person feels about him or herself and what he or she represents or is doing in their life. This includes self-awareness and a sense of self-worth, control over behaviour, realistic beliefs, spiritual appreciation or belief in purpose, independence, feeling safe and happy, appreciation of others and hope for the future.</td>
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<tr>
<td>Social wellbeing (interpersonal)</td>
<td>The interpersonal area concerns the ability to interact and to get along with others. Social wellbeing refers to the extent and quality of social interactions of children and youth, families and communities. This includes relationships with family members and peer groups, developing social networks, sense of belonging to a community, ability to communicate, social responsibility, empathy and participation in social and cultural activities.</td>
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Additionally the framework acknowledges that children and youth of different age groups require targeted psychosocial support services because of the vulnerabilities associated with
their particular age and developmental needs. The framework differentiates the following age groups (ibid):

- **0–6 years**: a high-risk group with specific health, nutrition and psychosocial needs as well as early childhood developmental needs. This is the age category used for measuring child mortality globally.
- **7–12 years**: typically primary school-going children with specific education and developmental needs and the age when life skills learning should begin.
- **13–17 years**: typically secondary school-going children and adolescents. Some will have dropped out of school and likely to be doing hazardous work, and will have specific needs in terms of sexual and reproductive health and psychosocial support as well as education, developmental and life skills needs.
- **18–24 years**: typically youth or young adults in higher education or vocational skills training institutions, out of school or in early employment
- Additionally there are also Family, Community and National levels

However, the framework does not mention children with disabilities, children living with a family member with disability or caregivers with disabilities.

### Understanding disability

The World Health Organization (2011) reports that 15% of the world’s population is living with at least one disability (up to 20% in resource poor settings) and that the number is increasing due to various factors including the rise in chronic diseases such as HIV (HEARD, 2011; WHO, 2006). People with disabilities (PWD) have therefore also been described as the world’s largest minority (United Nations, 2008). Data shows that 80% of PWD live in low-income countries, are poor and have limited or no access to basic services, including education and rehabilitation.

The United Nations Convention on the Rights of Persons with Disabilities (2009) says “disability results from the intersection between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.” The term disability is often the source of heated discussions as it means different things to different people. The medical model, the social model, and the WHO model of disability are the most commonly used models and are described hereunder:

#### The medical model

The medical model historically focuses on the dysfunction or impairment of the individual. It conceives disability as the outcome of impairment. Focusing on physical differences the model seeks to cure the impairment rather than address the disabling factors in the environment. It sees people with disabilities as people with bodies that are impaired, do not work and cannot
be productive. Often, this approach focuses on particular groups such as "the blind" or "the deaf". The medical model has been criticised because it reduces disability to a physical construct when in fact there are many dimensions that contribute to disability (HEARD, 2011).

**The social model**

The social model of disability asserts that the impairment in itself is not an obstacle for a person with disabilities, but is a socially-created problem that demands a political and social response. Disability in this understanding is caused by physical barriers, personal attitudes and other features of the social environment. Inaccessibility to buildings and difficulty using transportation are some of the barriers that limit full social participation of people with disabilities. This model seeks to change the environment in which people with disabilities live, work and play. The model focuses on changing society and not on curing the person (United Nations, 2008).

**The integrated International Classification of Function Disability and Health Model**

Over the last four decades, a gradual shift in the conceptualization of health and disability from medical and social models towards a combined model of disability has occurred. The International Classification of Function Disability and Health Model (ICF), developed by the World Health Organization, synthesizes the medical and social models of disability and creates a "bio-psychosocial" model which reflects the complex phenomena of disability.

In the ICF framework, disability is understood as a “complex phenomenon that manifests itself at the body, person and social level” (Üstün, 2001) and appears on three levels, namely body structure/function (impairment), activity level and participation in society. According to this model these three levels are outcomes of interactions between health conditions, the intrinsic features of the individual and extrinsic features of the social and physical environment (see figure 1).

Impairments of body structure or functioning are understood to be problems with the anatomical structure of the body (e.g. a missing limb) or its physical functioning (dementia, deafness, albinism, epilepsy, HIV infection). Depending on environmental (social and physical) and personal factors, this condition may or may not lead to activity limitations and/or participation restrictions. Activity limitations are understood as difficulties with executing a task or action (e.g. getting dressed, walking, reading) and participation restrictions are problems relating to involvement in life situations (accessing work or social life).
HIV can be integrated within the ICF model. On the one hand, HIV is a health condition that affects the immune system. With appropriate treatment this might never develop into further impairment or activity limitation. However, because of the stigma related to HIV the person might experience participation restrictions without any major activity challenges or impairments. On the other hand, a number of people living with HIV or AIDS (PLHIV) develop impairments/change in body functions (e.g. blindness, neuromuscular disorders, paralysis, HIV-dementia, or mental health issues such as depression) that have the potential to develop into activity limitations (disabilities) and/or lead to participation restrictions. People that develop activity limitations as a result of HIV-impairment might experience decreased mobility and limitations in domestic life, self care and care for others. Going further PLHIV might not be able to work anymore, be excluded from participating in leisure activities such as sport and recreation and might find it difficult to participate in parts of community life such as public gatherings, church visits, school events etc.

Children and disability

The 2010 EFA Global Monitoring Report reveals that 150 million children worldwide have a disability of which about four in five children with disabilities are in developing countries (UNESCO, 2010). In addition, many millions of children live in households with parents, dependants, carers or relatives who have disabilities. The report shows also that levels of
moderate and severe disability are higher in resource poor settings than in rich countries (ibid).

The UNESCO report also reveals that about 40 million out-of-school children have some sort of disability (that is about half out of a total of 72 million) and that this number is rising “due to increasing poverty, armed conflict, child labour, violence and HIV/AIDS” (ibid). Therefore it will be impossible to achieve the Millennium Development Goal two (MDG 2: achieve access to universal primary education) which is a crucial gap that has also been overlooked in the last MDG review (2010). Children with disabilities are less likely to be sent to school because it is physically not possible. Financial issues, fears of not coping, worries in regards to stigma and its effect on the wider family, such as siblings, might influence parents’ decision not to send their child to school (Ashcraft, 2006). As a result it is not surprising that the International Disability and Development Consortium estimate that 98% of disabled children in developing countries are denied any formal education (International Disability and Development Consortium, 1999). In addition, those children with disabilities who do go to school might have fewer demands placed on them, and therefore may learn less than their non-disabled peers (Yeo, 2001).

The link between poverty and disability has been widely described (Yeo, 2001). One of the most common concepts to express this interrelationship is the vicious circle of poverty and disability. The circle illustrates that poverty is a cause and driver of disability, which in turn, through social vulnerability, increases the risk of poverty. Children with disabilities (and possibly those living with disability) are not only less likely to go to school, but they also have limited access to health services, are more likely to live in poverty and are at increased risk of abuse including sexual abuse.

Because disability increases risks of poverty and decreases prospects of education this in turn increases social vulnerability including further risks of ill-health. In the UK Department For International Development (DFID) report on chronic poverty and disability Rebbaca Yao points out that people with disabilities “experience discrimination from birth, or from the moment of becoming disabled” (meaning impaired) (Yeo, 2001). The birth of a child with disabilities might be

Figure 2: Vicious cycle of poverty and disability

considered a tragedy. She further explains that “where there are limited resources it may be seen as economically irresponsible to give an equal share of resources to a disabled child who is perceived as unlikely to be able to provide for the family in the future” (Yeo, 2001). In the case of more severe disabilities this might even lead to negligence or death (Neubert & Cloerkes, 1994, Ashcraft, 2006). Children with disabilities might also be used to gain money through begging on the streets (Yeo, 2001) as their disability can be exploited for this purpose.

This reality exists despite the fact that in Africa the rights of children with disabilities and those living with disability are protected through the signature of many African states under the UN Convention on the Rights of Persons with disabilities (CRPD). In addition, a number of African treaties protect the rights of people and children with disabilities and although they are partially domesticated are seldom reinforced.

Table 3: African Human Rights Instruments that include disability

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<td>Includes the recognition of the rights “of the disabled” and that “they” are entitled to “special measures of protection”, it also recognizes the right to physical and mental health (article 16)</td>
<td>Recognizes the needs of the physical and mental development of every child as well as the rights of “mentally or physically disabled” children to special measures of protection, allocation of resources and access to public buildings and services (article 13)</td>
<td>Recognizes the right of women with disabilities to live lives free from violence and discrimination (article 23), the need to accommodate their “special needs and facilitate their access to employment, professional training and participation in decision making”</td>
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Psychosocial effects of disability on children

Children with disabilities have the right to the same care and support as their able bodied peers which includes consistent attention, care, stimulation and support from a primary caregiver. In addition they might need some additional support and accommodation of their special needs. The success of the attachment process facilitates the development of a child’s identity and security. The desire for love, affection and attention remains in the child as it grows to become a fully mature adult. However, children and youth with disabilities may face the risk of receiving inadequate emotional and social support from those around them. The lack of adequate emotional and social support may emanate from negative attitudes or
negligence as well as misinterpretations of what children with disabilities need. Some health conditions may require a child to be hospitalized, ultimately separating the child from their parents when attachment should be taking place. Other health conditions but also participation restrictions may keep a child for long periods at home resulting in less stimulation and developmental opportunities.

Additionally, children with disabilities may face other challenges, for example, barriers to physical access to services, negligence and negative attitudes from peers and adults. The latter might be connected to misinterpretations, myth, stigma and traditional beliefs surrounding disability. Peoples’ reactions to these misinterpretations might reduce social support and foster exclusion and through this limit opportunities for education, employment or participation in the community. These factors facilitate the isolation of children with disabilities which have the potential to lead to increased levels of stress and lower self esteem (UNICEF, 2005). Social isolation and restrictions of opportunities can also lead to anxiety and feelings of a lack of control over life situations.

Children with disabilities often have fewer opportunities to explore their environment as a result of their impairment as well as barriers in the environment. In addition, parents or caregivers might not be enabled to compensate for these challenges and as a result the child receives less stimulation and encouragement for its development. At school, children with disabilities are more likely to be bullied and harassed (ibid.), might have a limited number of friends, and engage in fewer extracurricular activities than their peers (Montie and Abery, 2011), all of which effects their psychosocial development.

**Self-image/ self-esteem**

Disability can affect the physical, emotional and cognitive development. A person’s physical, social, emotional and cognitive capacities are a fundamental part of their self-image and identity. The experience of disability can lead to negative self-image and low self-esteem, a feeling of being less competent than others (Hills, 2007). However overcoming challenges in an encouraging environment can also have the opposite effect and develop self-esteem and image.

The challenges of developing a positive self-image and identity are more evident at adolescence where adolescents are preoccupied with answering the question, *who am I?* They look outside the family for confirmation of their self-image and identity. Peer relationships are very important at this stage as they are a sign of belonging and acceptance. Negative attitude and outright rejection from peers result in anger and self-hatred, and lower self-esteem (Saskatchewan School Trustees Association, n.d.). Disability has effects on how an individual relates to the world and on future plans for career, education, and marriage (ibid.)
Adolescents who are rejected or ignored in their earlier years may grow up feeling unattractive. These feelings may give them an impression that they are unable to form any meaningful relationship including sexual relationships. In addition adolescents with disabilities might also be told that they are not supposed to have a sexual life while being encouraged to participate in any other part of life. They may therefore maintain regular social relationships to their peers yet at the onset of puberty may experience difficulties to understand their own feeling and to work out if and how to engage in sexual relationships on an equal basis with others.

**Participation and social inclusion**

Like any other child, children with disabilities benefit from having positive relationships and a sense of belonging at home, school and in the community. Unfortunately, children with disabilities may face social exclusion and experience negative societal stereotypes. In some cultures, disability is still understood as a result of witchcraft, evil spirit possession or a spiritual punishment from the ‘gods’ (Von der Assen, Euwema & Cornielje; 2010; Hanass-Hancock, 2009; Neubert & Cloerkes, 1994; Üstün, et al, 2001). Other communities perceive children and youth with disabilities as low performers, consequently demanding less and offering fewer opportunities for participation. Other children with disabilities might miss out on participation opportunities due to their parents’ over-protectiveness or feelings of shame and guilt which may lead to hiding their children from the community. Additionally, parents themselves might perceive their children as lacking skills to accomplish anything in an effective way. They might have little confidence in their children and do not encourage them to reach their full potential (Saskatchewan School Trustees Association, n.d.). Children who are not encouraged to explore their environment and potential however will eventually doubt their capacity which may lead to low self esteem, feelings of inferiority and helplessness. On the other hand there are many examples of parents who have supported their children against all odds and these parents show the potential and importance of caregiver-child psychosocial support for a child’s development.

**Protection**

As mentioned earlier, some cultures or communities believe that a child with disability is a product of a curse, an incestuous relationship, or a sin committed in a previous incarnation which has angered the ‘gods’. Some communities believe that such a child is evil and will bring misfortune to the family or the community. A child with disability in a community where such beliefs exist is at risk of physical, emotional, and verbal abuse (UNICEF, 2005).

It is essential to note that this abuse is not only perpetrated by adults but that some able bodied children and youngsters with disabilities are also agents of this abuse. Stigma and prejudice can result in socially sanctioned violence against children with disabilities in the
community (ibid.). Some individuals or communities perceive that children with disabilities are of no value hence whatever happens to them is not of concern. In other cases the perpetrator is a close relative, the bread winner for the family or a more powerful person in the community. In all these cases it is difficult to take the perpetrator to the police and court and as a result abuse might take place for many years.

Children with disability may find it difficult to protect themselves due to their lack of education on their rights, their lack of sexuality education and the lack of accessible judicial and child services that enable them to exercise their rights. For instance children who are hard of hearing or deaf without speech can find it difficult to explain what transpired if an interpreter is not present. Those who are visually impaired or intellectually disabled might be denied to identify their attacker as they are believed to be unable to do so.

Additionally there have been some descriptions that in some cultures sexual abuse was initiated through the belief that HIV can get cured by having sexual intercourse with a virgin. This puts children with disability at risk since some individuals perceive them as sexually inactive making them a target for this practice (Hanass-Hancock, 2009; Groce & Trasi, 2004).
THE INTER-RELATIONSHIP BETWEEN DISABILITY AND HIV

UNAIDS recognized, with its 2009 policy brief on disability and HIV, the interrelationship between disability and HIV (2009). However this interrelationship might play out more severely in epidemic areas like eastern and southern Africa (ESA). A recent study suggests that there is a very strong association between the two issues (see graph 1) which cannot be found elsewhere in the world. The data is not conclusive in relation to the directions or drivers of this relationship. However it reveals that the countries with the highest HIV prevalence are also the countries with the highest disability prevalence in the region.

Graph 1 Interrelationship of disability and HIV from (Hanass-Hancock, Regondi & Naidoo, 2012)

The relationship between disability and HIV in ESA is probably driven by a number of factors which will be described in more detail below. In summary, there are three main issues that need to be considered:

1. On the one hand people with disabilities (particularly children and youth) are at increased risk of exposure to HIV due to a number of risk factors such as increased poverty, lack of access to sexuality education and HIV information, decreased access to health services including HIV prevention and treatment, increased risk of sexual abuse, risky sexual behaviour and beliefs or myth surrounding sexuality of PWDs.

2. On the other hand people living with HIV (including children) are at risk of developing disabilities as a result of HIV or its treatment.

3. In addition some scattered evidence suggests that the increased burden of care-giving for a number of dependants in the context of multiple stressors (HIV, poverty, crime, lack of nutrition, aging) affects children’s prospects negatively and can lead to developmental delays and learning problems.
The interrelationship between disability and HIV might also affect high prevalence areas such as ESA to a much greater extent than other regions in the world. The urgent need to address the interrelationship between disability and HIV has been recognized internationally in the UN High Level Meeting (2011), which declaration includes 5 statements relevant to disability and HIV (see figure 3) as well as in the rapporteur session of the ICASA conference 2011.

**Figure 3: References to disability in the 2011 declaration of the High Level Meeting (HLM) on AIDS**

<table>
<thead>
<tr>
<th>References to disability in the 2011 declaration of the HLM (United Nations, 2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td>23. Welcome the adoption of the UN Convention on the Rights of Persons with Disabilities, and recognize the need to take into account the rights of persons with disabilities as set forth in that convention, in particular with regard to health, education, accessibility and information, in the formulation of the global response to HIV and AIDS;</td>
</tr>
<tr>
<td>31. Note with concern that prevention, treatment, care and support programmes have been inadequately targeted or made accessible to persons with disabilities;</td>
</tr>
<tr>
<td>60. Commit to ensure that financial resources for prevention are targeted ..... in order to ensure that resources for HIV prevention are spent as cost-effectively as possible; and ensuring particular attention is paid to women and girls, young people, orphans and vulnerable children, migrants and people affected by humanitarian emergencies, prisoners, indigenous people and people with disabilities, depending on local circumstances;</td>
</tr>
<tr>
<td>69. Commit to promote services that integrate prevention, treatment and care of co-occurring conditions, including tuberculosis and hepatitis, improve access to quality, affordable primary health care, comprehensive care and support services, including those which address physical, spiritual, psychosocial, socio-economic, and legal aspects of living with HIV, and palliative care services;</td>
</tr>
<tr>
<td>73. Commit by 2015 to address factors that limit treatment uptake and contribute to treatment stock-outs, drug production and delivery delays; inadequate storage of medicines, patient drop-out, including inadequate and inaccessible transportation to clinical sites; lack of accessibility of information, resources and sites, especially to persons with disabilities; sub-optimal management of treatment-related side effects; poor adherence to treatment; out-of-pocket expenses for non-drug components of treatment; loss of income associated with clinic attendance; and inadequate human resources for healthcare;</td>
</tr>
</tbody>
</table>
Children and adolescents with disability in the context of HIV

Children with disabilities are affected by HIV and AIDS as much as any other child, yet they have been left out of HIV and AIDS programming for a long time (Handicap International, 2011; Hanass-Hancock, 2009; UNAIDS, 2009; Groce, 2004).

It has been argued that part of the lack of attention to this issue is based on the assumption that children and youth with disabilities are not at high risk for HIV infection because they are asexual, do not use drugs and are not in danger of sexual exploitation or abuse. However, it is clear that these assumptions are false. The Global Survey on HIV and disability (Groce, 2004) identified that people with disabilities, including children with disabilities, are exposed to all known HIV risk factors and in some cases they are at increased risk of HIV. The available data was summarised in a recent review in the following way (Hanass-Hancock & Nixon, 2010):

1. **Poverty**: People with disabilities are often the poorest members of their communities, and the World Bank estimates therefore that persons with disabilities may account for 20% of the poorest citizens in the world. Children with disabilities as well as children who are cared for by a disabled family member are therefore at risk of living in poverty (Hanass-Hancock & Nixon, 2010; Groce, 2004; Yeo, 2001).

2. **Lack of education**: Children with disabilities worldwide are typically excluded or not accommodated at school because they are not considered in need of education, are assumed to be a distraction in class, or are believed to be incapable of learning. Even when in school, children with disabilities are less likely to receive science and health education and more likely to be excused from sex education courses and HIV information (ibid.).

3. **Lack of HIV and "safer sex" information resources**: There is a pervasive misconception that children and youth with disabilities are either asexual or oversexed. Although adolescents with disabilities are generally more socially isolated, they have been shown to be as sexually experienced as their able-bodied peers. Reproductive health awareness-raising programmes are known to frequently exclude or be inaccessible to people with disabilities. Adolescents or youth with disabilities are rarely the targets of HIV and AIDS interventions designed specifically to address their particular prevention needs and are less likely to have access to condoms or other prevention methods than their able-bodied peers. Research indicates that children and youth with disabilities have less knowledge about HIV and are as sexually active as their peers, yet with a low degree of condom use (ibid.).

In addition, research indicates that teachers of children with disabilities often feel uncomfortable with teaching sexuality education to these youngsters as they do not have the appropriate skill and tools available (Phillander & Swartz, 2006).
4. Elevated risk of violence and rape, and lack of legal protection: Abuse among children, and here in particular girls with disabilities, ranges from double to quadruple the rate of girls in general. Approximately 80% to 90% of persons with disabilities are victims of some type of abuse at some point in their lives. The few studies that exist indicate that women with a disability are more likely than non-disabled females to be physically or sexually assaulted by their partners and women with disabilities are more likely to be subjected to serious violence. However, education and legal protection is still lacking (Hanass-Hancock, 2009; Dickman & Roux: 2005, Groce & Trasi, 2004). In addition some research indicates that the myth and beliefs surrounding sexuality of PWDs are associated with increased risk of exposure to HIV. Research shows that PWD believe that some able bodied peers will sexually abuse them to cleanse themselves of HIV as they believe that PWDs are virgins (Hanass-Hancock & Nixon, 2010; Hanass-Hancock, 2009; Groce & Trasi, 2004).

5. Substance abuse: Drug abuse among PWD is reported to be significantly higher than the general population. Substance use is associated with elevated sexual risk-taking and may also lead to sharing injecting equipment, resulting in increased vulnerability to HIV (Hanass-Hancock & Nixon, 2010; Groce, 2004).

6. Vulnerability of disabled orphans: Children with disabilities who are orphaned have been found to be particularly vulnerable and are less likely to receive the same care and support as their non-disabled orphaned peers (Hanass-Hancock & Nixon, 2010; Groce, 2004).

7. Precarious access to affordable health care: Health care providers have been reported to routinely deny people with disabilities access to HIV testing and HIV and AIDS care. Lower priority is often placed on individuals with disabilities when scarce HIV medications and services might be rationed. Furthermore, people with disabilities face barriers to accessing any form of health care services (e.g., because clinics are often without ramps and Braille or sign interpreters), which can result in other sexually transmitted infections going undiagnosed and further increasing risk of HIV infection (Groce, 2004, Yeo, 2001).

8. Stigma: Stigma has been associated with HIV, as well as with disability. People with disabilities who become HIV positive may become doubly stigmatised. A further layer of discrimination may also be experienced by people who are not heterosexual (Hanass-Hancock & Nixon, 2010; Groce, 2004).

The few prevalence studies that are available confirm this claim. The latest national prevalence study from the Human Science and Research Council (Shisana, 2009) in South Africa, released in 2008, revealed that at 14.1% (see fig 2), HIV prevalence among the group of people with disabilities was higher than the national average of 10.6%. In this study, the group of people with disabilities showed higher prevalence rates than other key populations such as men who have sex with men. Studies in other African countries on the deaf population similarly indicate that deaf people are as likely, if not twice as likely (Touko, Mboua, Célestin,
Tohmuntain, Peter & Perrot, 2010; Taegtmeyer, 2008) to be infected with HIV as the general population. The vulnerability of people with disabilities to HIV and AIDS is in keeping with the general recognition that marginalised, stigmatised communities with limited access to their basic human rights are frequently at higher risk of HIV infection and they feel the impact of HIV and AIDS more significantly. Research shows that people with disabilities have higher levels of illiteracy, unemployment and poverty, and are at risk for sexual abuse and assault, factors generally linked to vulnerability to HIV and to a greater impact of HIV infection.

Figure 4: HIV Prevalence and People with Disabilities in South Africa (Shisana, O., et al, 2008)

Children and adolescents living with HIV and disability

UNAIDS estimates that about 2.3 million children live with HIV in the sub-Saharan region (UNAIDS, 2011). Children living with HIV may display developmental delays in regards to motor performance, cognition and experience adverse events such as skin complications, respiratory problems, fatigue, kidney disease and decrease in kidney function and even Attention Deficit Hyperactive Disorder (ADHD). In addition, mental health disorders such as depressions and anxieties have been reported in adolescents and youth living with HIV. The evidence in Africa is very sparse and scattered and it is difficult to provide a picture of the scope and extent of this issue despite the fact that, for instance, in South Africa 40-60% of all paediatric admissions to hospitals are estimated to be related to HIV (McCulloch & Ray, 2008; Kala, 2007). In addition children living with HIV and disability might be denied basic and developmental needs as a result of their physical condition, lack of knowledge on how to address disability as well as stigma. There is however very little knowledge available on the disabling effects of HIV in children. The following is therefore only a short introduction to start a discussion on this issue.
Motor development

While few papers in resource-rich settings assess issues of motor performance delays in children with HIV (Bruck, 2001; Chase, 2000; Wolters & Brouwers, 1998; Nozyce, 1994) even fewer are available for ESA (Ferguson & Jelsma, 2009; Potterton & Eales, 2001; Msellati, 1993). Some of the few researchers working on motor development and HIV in ESA are Potterton and Eales as well as Ferguson and Jelsma (Ferguson & Jelsma, 2009; Potterton & Eales, 2001). The former studied a cohort of children with antiretroviral treatment (ART) access and found that 40% of the patients in the infected sample had significant motor delay. The authors suggest that this delay could be related to inadequate muscle strength and activation of the Central Nervous System (CNS). The increased incidence of illness and hospitalization leads to periods of inactivity and decreased stimulation which affect the development of motor skills. A few years later Ferguson and Jelsma worked with children living with HIV also with access to ART (ibid.). Assessing a cohort of 51 HIV-infected children (24 were on ART) and 35 controls the authors found that the HIV infected sample had significantly more hospital admissions (P < 0.01), their caregivers were mostly single (P=0.04), and their motor performance was significantly poorer and delayed than in the age-matched sample (Jelsma, Davids & Ferguson, 2011). 67% of children living with HIV had significant motor performance delays. How developmental programmes or rehabilitation respond to HIV-related disability in children in ESA is not known.

Stunting and weight problems

Similarly the Ferrand et. al., (2007) study in Zimbabwe revealed high levels of growth problems in children living with HIV (sample 32 children living with HIV with recent access to ART). Almost all participants (97%) had below average height for their age and all were below the average weight. In 62% of the sample the growth delay was so severe that the authors identified this condition as “stunting” (ibid.). The children and adolescents in this sample (age 8-19) also reported a high incidence of parental ill health and mortality. 45% of these children and adolescents were caring for a sick parent, guardian or sibling which, in 19% of the sample, led to the regular missing of school (ibid.). Again how developmental programmes or rehabilitation respond in our region is not known.

Pulmonary problems and renal functions

Ferrand et.al. (2007) also investigated (32 participants) other HIV related complications. They found that adolescents living with HIV frequently reported problems with respiratory tract infections, tuberculosis, skin complaints and diarrhoea. The sample possibly included more recently infected adolescents than only those who grew up with HIV. Similarly, Nunes et.al. (2011) inquired into the impact of ART on decreasing invasive pneumococcal disease (IPD) in South Africa. Although the burden of IPD decreased by 50 % through the onset of ART, the risk
of IPD remains 42-fold greater for HIV-infected children compared to uninfected children (ibid.). Again this study does not go beyond the medical diagnosis. However IPD can be categorized as pneumococcal meningitis – a condition which can lead to serious damage to brain and nervous cells (brain damage and hearing loss), which, it could be argued, ultimately leads to developmental delays and disabilities. This has however not been further explored in the context of HIV in ESA.

Another study from Johnson et.al. (2000) inquired into the morbidity experience of children under five years of age in Rwanda. Their results found that the OVC status of the children influenced the risk of childhood morbidity, and here in particular diarrhoea, fever and ARI (acute respiratory infection) were found, which in turn influenced childhood development. Both studies are, however, very medically orientated and do not collect data in regards to the effects of morbidity on developmental delays or disabilities.

There are also a number of studies focusing on the renal dysfunction of people living with HIV; however there are only a few focusing on children in resource poor settings. McCulloch & Ray (2008) discuss data related to this topic. They describe that before the onset of ART in the US 40% of children living with HIV developed renal complications leading to poor growth, accelerated progress of AIDS and premature death (McCulloch & Ray , 2008; Kala, 2007; McCulloch, 2007). They describe a number of different renal dysfunctions/failures associated with HIV of which HIVAN (HIV acquired Nephropathy) is the most common. In adults this typically presents itself with the histology of collapsing kidney tissue (FSGS – focal segmental glomerulosclerosis) and microcystic changes (McCulloch & Ray , 2008). Children and adults affected by this condition can show signs of fatigue, weakness, inability to regulate water, shortness of breath and swelling. Articles focusing on renal dysfunction are usually very medical and do not describe what effects this condition has on the development of the child.

**Mental health**

There are quite a number of papers published which focus on the increased prevalence of mental health disorders in people living with HIV (Brandt, 2009; Smart, 2009), and these argue that depression, anxieties (more in women) and alcohol disorder (more in men) are increased in this population group due to a number of stressors. There is little research available in regards to children and adolescents living with HIV in resource poor settings such as ESA. Emerging studies in the US reveal a high prevalence of mental health disorders in youth living with HIV and associate this with stressful life events, disadvantaged residential neighbourhoods, the caregiver’s HIV status and child/youth awareness of HIV status (Kang, et al, 2011; Gadow, et al, 2010; Mellins, C.A., et al, 2009; Gaughan, et al, 2004). For instance, in the Kapetanovic et.al. (2011) study of 197 adolescents and youth living with HIV, 55% of the sample had at least one medically documented psychiatric diagnosis, 17% reported substance abuse and 74% had a history of at least one risky health behaviour. The studies often reveal
that social circumstances mediate mental health issues to a significant extent. Greater social support and acceptance of illness is also associated with lower levels of perceived HIV stigma, anxiety and depression (Andrinopoulos, 2011). The review could not locate any papers on issues of children living with HIV and mental health problems in resource poor settings; however given the body of evidence in regards to adults in resource poor settings and youth in disadvantaged neighbourhoods in richer countries it is plausible that children and youth living with HIV in resource poor settings are affected by mental health issues as well. More research is needed to understand this link.

**Other issues that have not been explored**

There is very little knowledge on other kinds of impairments or disability in children living with HIV in resource poor settings; however it is plausible that there will be a number of other adverse events similar to adults living with HIV. Most likely children living with HIV are affected by developmental delays caused through inactivity, lack of stimulation during episodes of illness, effects of opportunistic infections (e.g. TB, meningitis) and biomedical changes on ART, for instance changes in the nervous system (known in adults as HIV dementia), the sensory system (e.g. visual impairments) and the neuromuscular system (known as peripheral neuropathy in adults). One study was found that indicated an increased prevalence of Attention Deficit and Hyperactive Disorder (ADHD) in children living with HIV in South Africa (Zeegers, et al, 2010). However there is still a large gap in research in relation to HIV-related disability in children living with HIV.

**Care giving, HIV and disability**

It is estimated that almost 90% of the approximately 17 million AIDS orphans world-wide live in sub-Saharan Africa (UNAIDS, 2010). This does not include the growing number of children who are not orphaned but still in need of care as they are looking after sick family members. It is argued that the extended family, also described as the “traditional social security system” in the region (Freeman, 2006), has taken in the majority of orphaned children (Kuo & Operario, 2009; Freeman, 2006; Ansell & Young, 2004; UNICEF, 2003). Though family care is generally regarded as more beneficial for orphaned children than institutional care (Kuo & Operario, 2009; Freeman, 2006), it shifts the costs and stresses of caring to vulnerable individuals such as children, women and the elderly (UNICEF, 2003) and raises important questions of sustainability and is a cause of further marginalization (Hosegood & Timaeus 2006; Howard et al., 2006; Kakooza & Kimuna, 2006; Kipp et al., 2006; Campbell & Foulis, 2004; Steinberg et al, 2002; World Health Organization, 2002). This in turn provides risk factors of disability for those who are caring for people living with HIV including children and grandparents, as the burden of care increases the risk to develop care related health conditions while at the same time it decreases resources to address health issues in general. The risk might be greater for
child carers who are still growing and in need of care themselves as well as for older people whose bodies are also affected by the process of aging. The experience of both living with a disabled family member and providing care for biological and non-biological children, siblings or family members in the context of HIV has the potential to be a ‘double burden’. However, little attention has been paid to the particular experiences and needs of caregivers with disability and those caring for family members with disability in the context of HIV in southern Africa.

Limited evidence indicates that children who care for family members who experience disability are more likely to miss school. Empirical studies have shown that stressors related to care giving can negatively affect mental and physical health (Leder, Nicholson, Grinstead & Torres, 2007; Pinquart & Sorensen, 2007) as caregivers of orphaned children have poorer physical and mental health outcomes (Kuo & Operario, 2010; Joslin & Harrison, 2002). It could be argued that poor health status can lead to impairment such as musculoskeletal injuries as a result of excessive physical strain and worsened physical health; however little research is available that investigates these issues. Research from southern Africa does reveal that the demands of care giving can cause or exacerbate physical, emotional, financial and even ‘social’ stress (Hosegood & Timaeus 2006; Howard et al., 2006; Kakooza & Kimuna, 2006; Kipp et al., 2006; Campbell & Foulis, 2004; Steinberg et al, 2002). Particularly older caregivers and children might experience health risks through taking caring work responsibilities, since they are likely to have worse physical health outcomes and their new living arrangements and responsibilities may adversely affect their growth, ageing and wellbeing (Ssengonzi, 2009). Older carers may also care for or have lost their own children, and thus find themselves alone having to support a household on their pensions and forced to seek income-generating work at a time when they should be able to retire (Kimuna & Makiwane, 2007). The health risks of care giving will of course be greater where individuals are caring for a large number of children. As HIV is epidemic in ESA and a major cause of orphanhood and caring for sick relatives it exacerbates the vicious circle between care giving and disability risks (see figure 4).
Very little is known about this interrelationship and scientists have only started to describe the linkages between care giving and disability. Programmes supporting children should mainstream disability or develop and adjust approaches to accommodate the special needs of children with different types of disabilities.

Figure 4  Vicious cycle care giving and disability (Hanass-Hancock and Casale 2012)
PSYCHOSOCIAL SUPPORT FOR CHILDREN IN THE CONTEXT OF DISABILITY

The SADC PSS framework acknowledges that “children and youth of different ages require different psychosocial support services” and list four different age categories. The following chapter identify psychosocial issues that organizations should consider when programming for children with disabilities. For ease of use these sub-chapters have been aligned with the SADC PSS framework tables.

Table 5: Psychosocial domain of emotional wellbeing

<table>
<thead>
<tr>
<th>Age group / area of focus</th>
<th>Issues for children with disabilities</th>
<th>Relevant Psychosocial interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–6 years</td>
<td>Children with disabilities like all children require stimulation, love and care from a consistent caregiver. A child with disability may fail to give signals that can easily be interpreted by a caregiver hence may go without getting the required emotional or physical attention. Some children with disability are abandoned by their parents. Such children may be moved from one household to the next thereby depriving them of a consistent caregiver. Failure by caregivers to recognize what children with disability can do for themselves Children with disability are exposed to neglect or abuse.</td>
<td>Support children with disabilities to have a stable and nurturing relationship to a caregiver Provide caregivers with adequate information regarding how to nurture a child with a specific disability. The quality of nurturing (cuddling, stimulation, love and warmth) is important for the emotional, physical and cognitive development of the child. This information should enable caregivers to cope, become comfortable with the child and share hope for the future. Enhance capacity of caregivers to provide care for children with disability by establishing caregiver support groups. Develop programmes that protect children with disability from abuse.</td>
</tr>
<tr>
<td>Age Group</td>
<td>Issues and Challenges</td>
<td>Solutions</td>
</tr>
<tr>
<td>----------</td>
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<td>-----------</td>
</tr>
<tr>
<td>7–12 years</td>
<td>Inability to reach their goals because of disability may lead to frustration and a feeling of helplessness and inferiority. Negative attitudes and outright rejection from peers, caregivers and community may lead to lower self-concept and self-esteem. Sexual abuse particularly of girls with disabilities</td>
<td>Programmes to provide access to education. Education brings independence. School activities should include awareness programs so that negative attitudes to disability can be dealt with at school. Can also include activities that involve the family and community awareness to fight stigma and promote acceptance of CwDs. Promote meaningful participation of Children with disability and the respect of their views, as a group that holds vital knowledge around their experiences and therefore the best resource to understanding the approaches to tackle their needs. Develop programmes that provide stress, depression and trauma counselling for children with disabilities. Develop sensitive child and youth services to support abused children.</td>
</tr>
<tr>
<td>13–17 years</td>
<td>Sexual abuse particularly of girls with disabilities Children with disability who mostly rely on others to get tasks done will find it difficult to have a positive self-image and identity. Transition from childhood to adulthood can cause a lot of stress. Children with disability may perceive that they do not have the capacity to take up new roles as student, employee, employer, wife or husband.</td>
<td>Disability sensitive abuse services (including at the police and court) Have programmes that empower children with disability to make their own choices with regards to their future Provide guidance and counselling services for children with disability</td>
</tr>
</tbody>
</table>
### Table 6: Psychosocial domain of social wellbeing

<table>
<thead>
<tr>
<th>Age group / area of focus</th>
<th>Issues for children with disabilities</th>
<th>Relevant Psychosocial interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–6 years</td>
<td>Children with disabilities may have limited opportunities to explore their environment which can lead to failure to develop meaningful social relationships with other children.</td>
<td>Support for healthy relationships and attachment with caregiver and other children. Development of a strong support system which should include the whole family and community. Connect the family to Early Childhood Development services that provide support to children with disability.</td>
</tr>
<tr>
<td>7–12 years</td>
<td>Children with disabilities have less access to schools, learning and recreational facilities. Disability can alienate children from normal interactions with their peers and their Social circles.</td>
<td>Provide age, gender and disability appropriate recreational activities. Create a friendly environment that will enable children with disability to enrol and stay in school. Create an environment which will allow children with disability to receive support from peers within the school.</td>
</tr>
<tr>
<td>13–17 years</td>
<td>Children with disabilities have limited access to recreational activities. Taking part in recreational activities helps children with disability to form new relationships. Perceived lack of physical attractiveness can affect their (children with disability) social and sexual relationships. Children have the desire to be accepted and belong to a group.</td>
<td>Age, gender and disability appropriate recreational activities e.g. sport, drama clubs. Programmes should expose children with disability to role models including people with disabilities. Establish support groups or self help groups.</td>
</tr>
</tbody>
</table>
### Table 7: Psychosocial domain of skills and knowledge

<table>
<thead>
<tr>
<th>Age group / area of focus</th>
<th>Issues for children with disabilities</th>
<th>Relevant Psychosocial interventions</th>
</tr>
</thead>
</table>
| 0–6 years                | Children with disabilities may have limited opportunities to explore their environment which can affect cognitive development and can also lead to failure to develop life skills.  
Failure to be independent from their parents or caregivers  
Failure by caregivers to recognize what children with disability can do for themselves | Focus on developing the skills of children with disability by creating safe spaces that will allow them to safely explore their environment. This will foster a sense of autonomy and allow for the development of new skills.  
ECD centres should be equipped to ensure that children with disability have the opportunity to explore their environment.  
Focus on building skills of caregivers to support children with disability. |
| 7–12 years               | Children with disabilities have less access to schools and learning  
Disability interferes with the child’s need to explore their environment and learn new skills which are essential for successful adulthood.  
Inability to compete with peers both academically and on the sports field can lead to a sense of incompetence | Connect children with disability to inclusive education and special needs support.  
Develop programmes that focus on building the life skills of children with disability |
| 13–17 years              | Children with disabilities have limited access to sexual reproductive health education  
Children with disability may have poor education and poor preparation for vocational life after school | Develop and provide gender and age appropriate sexual reproductive health information in the correct mode and accessible to children with disability.  
Provide vocational training for children with disabilities and for potential employers |
Table 8: Cross cutting issues

<table>
<thead>
<tr>
<th>Area of focus</th>
<th>Issues for children with disabilities</th>
<th>Relevant interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>Community might mystify disability and cultural beliefs might disadvantage children with disabilities (e.g. by keeping children with disability at home)</td>
<td>Sensitization and anti-stigma interventions addressing misconceptions about disability Community conversations on how we can help families in which there is disability Increase understanding for psychosocial needs of children with disabilities</td>
</tr>
<tr>
<td>Environment</td>
<td>Public places, services and homes are not accessible to children with disability</td>
<td>Providing access to public services and places through developing universal designs (e.g. ramp in hospital) – maybe develop a checklist for accessible public buildings</td>
</tr>
<tr>
<td>National System</td>
<td>HIV policies and National Strategic Plans do not address issues of children with disability</td>
<td>Mainstreaming of disability in all child and HIV related national documents such as NSPs, PRPs and children and HIV Acts and policies Supporting caregivers is essential Counselling support for carers, financial or material support for carers Strengthen referral system</td>
</tr>
</tbody>
</table>
MAINTREERING DISABILITY

Disability like gender needs to be mainstreamed across programmes. This applies to including disability within data collection and monitoring as well as within policies and programmes.

Two key concepts of disability mainstreaming are laid out in the UN CRPD which has been signed by many African countries (United Nations, 2008). It stresses that services need to be offered with a “universal design” and that people with disabilities have to be “reasonably accommodated”. Within the UN convention “universal design” is understood as designing “products, environments, programmes and services so that they are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (ibid.). Building ramps within a school or hospital, using pictures and signs within sexuality education and providing a disability desk are such universal designs.

Examples of disability inclusive frameworks and toolkits

**Education**


**VCT counselling**


In addition to this, “reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others...” (ibid.). Providing a wheelchair, crutches, sign interpreters, material in Braille and disability sensitive material for sexuality education is such an adaptation. In some cases this might involve the training and sensitization of service providers in the health and judicial system.
Examples of reasonable accommodation of disability

Sexuality Education


Access to judicial system and justice in rape cases


In regards to HIV and AIDS, the NSP task group on disability and HIV (NSP task group on disability and HIV, 2011) has recently developed a disability inclusive framework. This framework was launched at the ICASA conference in Addis Ababa 2012 and provides a useful guide on how to include disability within National Strategic Plans on HIV.

Historically, disability is an under researched and neglected issue. Monitoring and reporting on disability has been dominated by a medical model of impairment for many decades and was usually collected in main disability categories such as “deafness”, “blindness”, “Intellectual disability” and “physical disability” (sometimes this also included mental health and sometimes mental health issues and intellectual disability were mixed up). Beside the conceptual challenges of this approach (as it does not include for instance different degrees of visual impairments and activity limitation and participation restrictions) the data collection was also often criticised as people with disabilities were not approached in national surveys as the fieldworker could, for instance, not communicate with them or did not reach out to them (e.g. a hidden child with disability is difficult to locate). In addition many national surveys do not even include a disability indicator (e.g. HIV prevalence studies, old DHS) and there is therefore little information on disability in relation to various issues including HIV and AIDS.

However in recent years a new disability indicator has been developed by the Washington Group. This indicator was used for the World Disability Report [6] and has been developed on the basis of the ICF framework. It includes a simple set of 6 questions that can be inserted into any kind of study or evaluation process and provides some basic data on disability. The disability indicator is not very strong in identifying mental health problems and in some projects a screening tool might be added for this purpose. The indicator is also just one of many available.

The review has also identified a number of research gaps and lack of information which is crucial to inform disability inclusive programmes:

1. In terms of clinical and health services, we need to better understand the changing nature of disabilities in children and young people and how different courses can be predicted.
2. We also need to find mechanisms to minimize the effects of disability for children/ young people to engage in age appropriate activities. So we need to know what characterises a successful transition from adolescence to adulthood by children with disabilities and how the health system might promote/ enable such a successful transition.
3. Further we require more research on the social, economic and structural determinants of chronic disease, including HIV and AIDS, among children and adolescents – what
determines whether these conditions become disabling (e.g. young carers, older and burdened grannies who are carers, erosion of extended family system)

4. We need more population based research to understand the extent and scope of a) HIV-related disability in children living with HIV b) risk factors of children with disabilities (e.g. sexual abuse).

5. Finally we need evaluations of disability inclusive and disability specific intervention in order to identify good and feasible practices.

Further thought is also needed in regards to the integration of children with disability into PSS programmes. In general, integration would include 1) Screening to identify children with disabilities 2) Development of feasible referral systems 3) Following general accessibility guidelines in all programmes (e.g. a disability accessible checklist ensuring universal design), 4) Development of specialized programmes where necessary (ensuring reasonable accommodation e.g. sexual abuse).
CONCLUSIONS AND SUGGESTIONS FOR FURTHER ACTIONS

Children with disabilities, those living with a disabled household member and their carer are particularly vulnerable to a number of stressors that have the potential to influence the child’s psycho-social wellbeing and development. The context of HIV might exacerbate this and exposes children to additional risks. PSS programmes focus on children’s wellbeing and here in particular at vulnerable groups and are therefore more likely to address the issues arising for children with disabilities in the context of HIV. The paper discussed current knowledge around the interrelationship of disability and HIV in regards to children as well as identified gaps in knowledge. Leading from this paper, suggestions for further actions can be provided in regards to advocacy, research and capacity building.

Suggestions for further actions

**Stakeholder engagement and advocacy**

1. Stakeholder discussion workshop to define an agenda for PSS of children living with disabilities. This discussion could clarify the drivers of change in policy for children with disabilities and their caregivers e.g. economic, service, and/or social change.

2. Development of an issue brief on children with disability and PSS in the context of HIV. This could highlight the most important facts from this discussion paper and the stakeholder workshop.

3. Establishing initiatives to advocate for PSS of children living with disabilities and interlink this with the regional initiatives on disability and HIV. Elements could include discussion on children with disabilities’ rights, integration and co-ordination of services, clearly defining their needs.

**Research**

1. Review new National Strategic Plans on HIV (NSP) as well as Poverty Reduction Strategies (PRS) in regards to the inclusion of children with disabilities.

2. Advocate for the inclusion of disability indicators in national surveys and assess the data with a disability lens.

3. Carry out research to assess the holistic needs, including health, education, environmental, social and cultural needs, and emotional needs of children with disabilities.
4. Carry out research that identifies a suitable screening process for disability (including screening tools) as well as a rehabilitation approach that is feasible and sustainable for eastern and southern Africa.

**Capacity building and interventions**

1. Develop an anti-stigma toolkit/reference material to address the PSS needs of children with disability.

2. Develop a toolkit that provides information on how to include disability in PSS programmes. This should focus on different areas as identified in the SADC PSS framework (see table 4-6). This toolkit could also be provided in the form of a best practice guide highlighting certain key areas such as sexuality education, sexual abuse and exploitation, psychosocial wellbeing or early childhood development.

3. Develop an intervention in regards to addressing sexual abuse in children with disabilities. The Save programme in Cape Town (a programme that focuses on sexual abuse cases of people with intellectual disabilities) could provide a good practice base on which this could be developed.

4. Promoting support mechanisms for children living with a disabled household member. This could be linked to the support of care giving in general as well as to poverty alleviation strategies.

5. Mobilising and supporting parents of children with disability as well as those of children living with HIV through support groups. Provide safe spaces for these parents to discuss issues with their peers.
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