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Care arrangement, grief, and psychological problems among children orphaned by AIDS in China

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Abstract

The China Ministry of Health has estimated that there are at least 100,000 AIDS orphans in China. The UNICEF China Office estimates that between 150,000 and 250,000 additional children will be orphaned by AIDS over the next five years. However, limited data are available regarding the socio-demographic characteristics, care arrangement, barriers to appropriate grief resolution and psychological problems among AIDS orphans in China. In this article, we review secondary data and reports from scientific literature, government, non-governmental organizations, and public media regarding children orphaned by AIDS in China to address their living situation, bereavement process, and psychological problems. Our review suggests that AIDS orphans in China are living in a stressful environment with many orphans struggling with psychological problems and unmet basic needs such as food, shelter, education, and medical care. Based on our review, we suggest that future studies should address the psychosocial needs of AIDS orphans in China and develop health promotion programs to mitigate the negative impact of parental death on the physical and psychosocial well-being of these orphans.

Keywords

AIDS orphans; China; grief; care arrangement; psychological problem

Introduction

The AIDS orphan crisis is attracting increased attention worldwide. It is estimated that 18 million children in Sub-Saharan Africa alone will be orphaned by AIDS by the year 2010 (UNICEF, 2005). A substantial literature exploring the impact of orphanhood on the well-being of children has emerged in the past few years. A wide range of topics has been discussed in the literature, including living situation, physical health, schooling, bereavement process, and psychological well-being (Makame, Ani, & Grantham-McGregor, 2002; Masmas et al., 2004; Monasch & Boerma, 2004; Safman, 2004; Nyamukapa & Gregson, 2005; Sarker, Neckermann, & Muller, 2005;).

Findings from the literature suggest that orphans are generally disadvantaged compared to non-orphans. Although most orphans are frequently cared of by extended family members, these orphans are more likely to live in households with less favorable dependency ratios and greater experiences of financial hardship (Monasch & Boerma, 2004; Nyambedha, Wandibba, & Aagaard-Hansen, 2003a; Nyambedha, Wandibba, & Aagaard-Hansen, 2003b; Oleke, Blystand, & Rekdal, 2005; Safman, 2004). Orphans have lower school attendance, lower school completion rates, and/or are less likely than non-orphans to be at the age-appropriate grade level (Bicego, Rutstein, & Johnson, 2003; Makame et al., 2002; Monasch & Boerma, 2004; Nyambedha et al., 2003b; Nyamukapa & Gregson, 2005). Although mixed results about physical health and health care access have been reported among orphans as compared with non-orphans (Crampin et al., 2003; Lindblade, Odhiambo, Rosen, & DeCock, 2003; Mamas et al., 2004; Nyambedha et al., 2003a; Nyambedha et al., 2003b; Sarker, Neckermann, & Muller, 2005), psychological problems have been consistently observed among orphans (Atwine, Cantor-Graae, & Bajunirwe, 2005; Cluver & Gardner, 2006; Makame et al., 2002; Pelton & Forehand, 2005). Orphans have markedly increased internalizing problems and higher levels of anxiety, depression, anger, and depressive disorders, as compared with their counterparts (Atwine et al., 2005; Makame et al., 2002). In a study among African American children 6 to 11 years of age from New Orleans, in addition to internalizing problems, orphans were also found to have clinical levels of externalizing problems before their mother's death (Pelton & Forehand, 2005).

Most studies of this nature have been conducted in Sub-Saharan Africa. The situation of AIDS orphans in Asian countries has received little attention despite the rapid growth of the AIDS epidemic in many Asian nations and regions including China. In China, although the HIV prevalence among the general population is still relatively low, high seroprevalence rates have been reported in selected locations and/or populations. Since the first outbreak of the epidemic among injection drug users (IDUs) in a southwest town in 1989, HIV has spread rapidly among IDUs and their sexual partners in provinces along the drug-trafficking route (Beyrer et al., 2000). In central China, thousands of farmers became infected with HIV during the late 80's to the mid-90's when they sold their blood to commercial blood collection centers (Rosenthal, 2002). The farmers, who were not tested for HIV, hepatitis B, hepatitis C, or other blood-borne infections, gave blood to collection centers, which pooled the blood of several donors of the same blood type, separated the plasma, and injected the remaining red-blood cells back into individual donors to prevent anemia. Farmers often remained for weeks at the centers, making repeated donations for cash. Such procedures, plus the reuse of contaminated needles and equipment enabled the rapid spread of the virus through the local population. Although the Chinese government has banned commercial blood/plasma collection centers since 1998 (Shenzhen Daily, 2003), the infection has spread widely among former commercial blood/plasma donors and their spouses. The average HIV prevalence rate in this population was 10–20%, and even exceeded 60% in some communities (UNAIDS, 2003). Many HIV-infected individuals have progressed to AIDS and thousands have died (Rosenthal, 2002). The China Ministry of Health has estimated that there are at least 100,000 AIDS orphans in China (CCTV, 2004a); the UNICEF China Office estimates that between 150,000 and 250,000 additional children will be orphaned by AIDS over the next five years (ACF, 2004).

Findings of studies in African countries may not reflect the situation of children orphaned by AIDS in China for several reasons. First, the majority of HIV infected adults in Africa are infected through unsafe heterosexual acts, while in China, the major modes of transmission are injection drug use and blood/plasma donation, although heterosexual transmission is on the rise (Yang et al., 2005). Children whose parents are infected with HIV through drug use or commercial blood/plasma donation may face different challenges in their lives compared to children whose parents contract HIV through heterosexual transmission. Second, the cultural differences between African countries and China may influence the bereavement process of

AIDS orphans. Third, while there has been public awareness of the orphan crisis in Africa for several years, prior to June 2004, the Chinese government had downplayed the existence of an AIDS orphan problem. Thus, in China, minimal social and emotional supports had been provided to AIDS orphans. Identifying the impact of orphanhood on children in China is essential for the welfare of these children in particular and for the prosperity of the society in general. In this paper, we review studies and reports from scientific literature, government, nongovernmental organizations (NGOs), and public media regarding children orphaned by AIDS in China to address their living situation, bereavement process, and psychological problems.

Methods

Several methods were employed for obtaining the literature and reports relevant to AIDS orphans in China. First, MEDLINE was searched for articles published in peer-reviewed journals. Second, the China Periodicals Database, one of the most comprehensive Chinese scientific literature databases, was searched for available Chinese articles published in major peer-reviewed journals. Third, online searches were conducted using Google for media articles and documents available on Internet including reports and unpublished data from both government and NGOs. Key words/phases, either alone or in combinations, were used for the searches, including AIDS orphans, children affected by HIV/AIDS, China, and Chinese. Through these various forms of searches, we identified one English journal article (Yang et al., 2006), four Chinese journal articles, five reports from governmental agencies and NGOs, and 24 media/Internet articles. After initial screening of the articles/reports, three Chinese journal articles and 15 media/Internet articles were excluded from further review because of redundancy or irrelevancy of the content.

Results

Socio-demographic characteristics of AIDS orphans

There are no national statistics regarding AIDS orphans in China. Small scale epidemiological surveys have provided some preliminary data on their socio-demographic characteristics.

In July 2003, a UNICEF-sponsored epidemiological survey ("2003 UNICEF survey") among 251 AIDS orphans and their caregivers in 5 agriculture counties in China (Xu et al., 2006) found that 54% of these orphans were boys, and 81% were 10–14 years old. Among these children, 29% were double orphans (either lost both parents or lost one parent and were abandoned by their surviving parent) and 71% were single orphans. About 58% (145/251) of these orphans lived with their surviving parent, 25% (63/251) with their grandparents, 6.4% (16/251) with aunts/uncles, 4% (10/251) lived by themselves, 4% (10/251) lived with neighbors, and 1.2% (3/251) lived in orphanages. In late 2003, the China National Commission for Next Generation (CNCNG), also sponsored by the UNICEF, conducted a similar survey among 231 AIDS orphans from 7 counties in three Chinese provinces and found a similar socio-demographic profile: 70% AIDS orphans were 11–14 years old, 28.6% were double orphans, and 71.4% were single orphans including 61 maternal orphans and 104 paternal orphans (CNCNG, 2003).

In both the 2003 UNICEF and 2003 CNCNG surveys, about 60% of the orphans lived in a family with an annual household income less than 1,000 Yuan (US\$125), 26% between 1,001 to 2,000 Yuan, and 13% above 2,000 Yuan (US\$250). Among AIDS orphans, one quarter (about equal numbers of boys and girls) had left school. Among those orphans quitting school, 41% were 6–8 years old, 16% were 9–11 years old, and 43% were 12–14 years old. Financial hardship was the number one reason for leaving school (48%). Among those leaving school, 62% left either before or within one year of their parents' death. Among orphans in the 2003

CNCNG survey, about 44% of orphans reported that they had to do more household chores or outside work for the family after the death of their parent(s).

Yang and colleagues examined data collected in 2001 from 266 households with HIV-infected intravenous drug users in Yunnan Province (Yang et al., 2006). Of the 266 households interviewed, 49% reported having one or more children ≤ 15 years of age, and 23% had children ≤ 5 years old, with a total of 213 children ≤ 15 years old. Children were evenly distributed by sex and age-groups, and 86 (40%) had lost at least one parent. During the previous year before the survey or the year before the infected parent died, approximately one-half of the children experienced family problems including frequent parental dissonance and/or expressions of desire to divorce. Approximately one-half of the children resided in households in which family members felt shameful about having an infected family member, or were afraid of contracting the disease from the infected. Thirteen percent of children lived in a household where family members perceived alienation by their neighbors. Orphans, compared to non-orphans, were significantly less likely to be currently attending school (49% vs. 79%). Children at ages 11 to 15 had significantly lower school attendance rates compared with children at ages 8 to 10.

In 2002, the Aizhixin Health Education Institute, a Beijing-based NGO, conducted a survey among 426 children (47% girls) from 225 HIV-affected households in two villages in Henan province, an agricultural province in central China with a population of 96.66 million (73% rural residents). It was estimated that one million poor peasants in Henan province were infected with HIV through unhygienic blood/plasma collection (Rosenthal, 2002). Among the children interviewed, 13.6% were < 5 years, 39.7% were 5–9 years, 52.3% 10–14 years, and 6.8% 15–17 years. More than one-third of the households had lost at least one parent to AIDS (11% lost both parents, 38.3% lost father, and 50.7% lost mother). Among households with at least one surviving parent, 88.3% reported that the surviving parent(s) had shown AIDS symptoms (Wang, 2003a).

During the preparation of this report, we analyzed 2001 data available to us from two Henan villages containing the basic demographic characteristics of those who were infected with HIV and those who died of AIDS. In Village One, there were 138 deaths (54% men and 46% women) and 151 known HIV-infected individuals (40% men and 60% women). The average age was 42.25 years (41.93 for men and 42.61 for women) for the deceased (at the time of death) and 40.73 years (41.43 for men and 40.26 for women) for those infected. The average family size was 4.51 for those deceased and 4.48 for those infected. In Village Two, 23 families had experienced at least one death and an additional 84 families were HIV-infected. Among the 23 families with AIDS-related deaths, 21 (91%) families had young children (< 15 years old) with an average 2.38 young children per family. The average age was 40.52 years (39.25 for men and 41.91 for women) for the deceased (at the time of death) and 39.25 years for those infected (37.98 for men and 40.65 for women). It was reported that the ratio of orphans to AIDS patients in China is around 2:1 or higher (Brown, 2004).

Care arrangement

In most areas of China, AIDS orphans are cared for by their surviving parent or by extended families (grandparents or relatives). Few public orphanages (for abandoned children or children orphaned by causes other than AIDS) accepted AIDS orphans because of the stigma and fear associated with HIV/AIDS. With funding from both central and local governments, a number of AIDS orphanages (“Sunshine Houses”) have recently been built in areas hit hardest by AIDS in Henan Province. However, the Chinese Ministry of Civil Affairs, which funds most of the AIDS relief efforts including AIDS orphanages in China, defines AIDS orphans as children who have lost both parents (CCTV, 2004b). Therefore the government-sponsored orphanages only accept a limited number of double orphans who did not have an extended family who could take care of them. All single orphans and some double orphans are in family-based care.

Although there have been discussions of more government-sponsored programs for AIDS orphans (CCTV, 2004a, Xinhuanet, 2005), many public health workers and AIDS activists do not consider this to be the best care arrangement based on the experience of orphan care in Africa and western nations (CCTV, 2004a, Gao, 2004).

Because of the stigma and fear associated with HIV/AIDS, few non-family households adopt AIDS orphans in China (Wang, 2003b). The government has promised financial subsidies for families caring for AIDS orphans. The Henan government announced in 2004 that families adopting AIDS orphans were entitled to 130 Yuan (\$15) living subsidy each month for three years for each orphan adopted. However, because over 80% of the relief funds are supposed to be provided from provincial revenues, the program has not been fully implemented. In addition, because of the overwhelming poverty in local communities, the government subsidy and assistance from other sources (e.g., private donation) have not always been used for AIDS orphans (Gao, 2004).

Barriers for grief among AIDS orphans in China

When death of a beloved person takes place (even when the death is expected), individuals may experience a wide range of emotions, commonly referred to as “bereavement and grief”. Psychologists and grief theorists describe bereavement as the state of having suffered a loss, grief as the normal reaction one experiences in that state, and mourning as both an intra-psychic process and cultural response to grief (Rando, 1984; Sanders, 1986). Every culture has a specific and direct influence on bereavement and grief among children. The Chinese view of death and grief is largely rooted in the traditional Chinese collectivist culture, taking the perspective of the group (e.g., family, community, society) rather than the individual (Nisbett, 2003). Besides the universal barriers for grief resolution among children (Rando, 1984; Sanders, 1986), some aspects of the Chinese culture may complicate the grieving process among AIDS orphans.

Most orphans are unaware of the cause of their parent’s death—Experts in childhood grief recommend that early disclosure at developmentally appropriate times about the facts surrounding the death is important for the grieving process. However, because individuals and families with HIV/AIDS are strongly stigmatized in China (Liu, et al., in press), parents are often reluctant to tell their children the cause of their illness or impending death. In the 2003 UNICEF survey, approximately 71% of Chinese AIDS orphans knew or suspected that their parents were going to die prior to their parents’ death, but only 12% had been told of this by their parents and 26% by other people. Only 40% knew the cause of their parents’ death (30% said it was HIV, and 10% said it was a blood disease) (Xu et al., 2006). Similarly, only 60% of the orphans in the 2003 CNCNG survey had known or suspected that their parents had been terminally ill; 95% of these children were not aware of the type of disease affecting their parents (CNCNG, 2003).

Inability to express grief—Chinese are taught from childhood to control emotions that are considered adverse or disruptive to harmonious social interaction (Tseng & Wu, 1985). Any excessive expression of grief and mourning is considered socially inappropriate. Individuals expressing too much emotion are considered to be “weak” in spirituality and devalued by society. Compounding this perspective, there is a cultural belief that children do not have emotional problems and a sense that family issues are private. Few children or adults would be comfortable openly grieving or willing to discuss bereavement-related family issues (particularly issues associated with shame or stigma) with non-family members. Therefore, children’s needs to express their emotions during bereavement are largely ignored or misunderstood in Chinese culture (Tseng & Wu, 1985).

In the 2003 UNICEF survey (Xu et al., 2006), all AIDS orphans reported feeling depressed when their parents died (except those who were too young to understand at the time of their parents' death). However, only 4% of these children had shared their feelings with others. In contrast, 37% said that the only thing they wanted to do with their suffering was to "keep it inside", 35% said they did not want to tell, and an additional 16% said they did not know whom to tell. In the 2003 CNCNG survey (CNCNG, 2003), 63% orphans reported feelings of fear, worry, and pain when their parents become ill, but only less than 14% of these children had shared their feelings with others or asked others what to do. About 29% said that they just wanted to keep their suffering inside. Among the 45% of children who said they would be willing to discuss their suffering, one-third said that they did not know whom to tell and two-thirds said they did not know how to tell.

Stigmatization—Chinese AIDS orphans may be stigmatized for multiple reasons. First, they may face social stigmatization against HIV-infected individuals and their families. In 2004, the UNICEF China Office sponsored a 6-day Summer Camp entitled "Together We Grow Up" in Beijing to which 72 children orphaned by AIDS from several provinces were invited to participate. Camp organizers initially contacted about 40 hotels, guest houses, and schools in Beijing over a two-month period and could not find a single place willing to host the orphans. The hotel owners feared that their guests would leave if they knew that AIDS orphans were staying in the same hotel, while school administrators said students were not willing to leave their dormitories to AIDS orphans (Xinhua, 2004).

A 9-years-old girl in China whose parents and older brother were infected described her experience after the death of her parents: "My father and mother died one after the other last year and the secret [AIDS in the family] became known to everyone in the village. The third day after my mother died, we were forced to move from the middle section of the village to the east end of the village. My brother concealed his real identity and went away to become a migrant labor" (CARN, 2004).

These children may also face stigmatization merely because they are orphaned. The continuous primary theme or value in social structure among Chinese throughout history has been the centrality of the family (Chin, 1996; Kim, Yang, Atkinson, Wolfe, & Hong, 2001; Tong & Spicer, 1994). It is considered shameful for individuals (even children) if the family is dissolved for any reason (e.g., divorce, parental death). Further, they may be stigmatized because the death of their parent(s) may signify "bad fate". Chinese culture values the social or natural "order" of life. Things are considered as "normal" if they follow a social or natural order; and "abnormal" otherwise. Chinese consider three types of death as "bad", signifying bad fate for the family: for a young child to lose a mother, for a middle aged man to lose a wife, and for an elderly person to lose a son.

Lack of adequate care—Because of the role of family in life, the extended family is expected to take care of a child when parents die (Phillips & Pearson, 1996). It is considered a disgrace to the extended family if an orphan is adopted by a non-family member. However, such a cultural norm, which prevents appropriate adoption by non-family members, has placed many AIDS orphans in environments lacking adequate financial support. Among the 251 orphans in the 2003 UNICEF survey, 45% (113/251) lived in a disadvantaged family environment (e.g., with an infected surviving parent, a single or disabled grandparents, or no adult) that is less likely to provide AIDS orphans with adequate social and emotional support.

Examples of psychological problems among Chinese AIDS orphans

Data regarding the mental health of AIDS orphans in China are not available since the Chinese government did not publicly acknowledge the existence of AIDS orphan problem until June

2004. However, numerous personal testimonies from AIDS orphans and observations from individuals who directly interacted with AIDS orphans suggest acute or potential psychological problems among AIDS orphans.

Desperation—“[After both parents died] my family was left with only my 11-year-old brother and me. Our parents left us with several thousand ‘jin’ [0.5 kg] of wheat, a little cash, an ox and a piglet. They were all taken away by our uncles. My brother and I could only stare in hunger at the three empty rooms. I remember I often dreamed of my parents making meals for the two of us. But when I woke up, I again faced the empty clay room, listening to wind and rain.” (17-year-old girl) (Inter Press Service, 2005).

Anxiety—One 13-year-old AIDS orphan named Zhu Bing whose father had died of AIDS and whose mother had AIDS and was in the last stage of the disease, described his life in the winter: “the weather is so cold, but my family does not have money to buy coal. ..I am so scared that my Mom will catch cold, as the doctor said that she would not be able to survive if she catches one. Because I am not a real AIDS orphan [by government’s definition], the county government does not give us money. But our life is even harder than that of the [double] orphans” (CARN, 2004).

“Despair and loneliness used to take over my life when my mom died of AIDS in 2002. Now my dad is suffering from the horrible disease. How I wish I could help relieve his pain” (10-year-old girl) (China Daily, 2004).

Loneliness—“[after my parents died] the kids in the village did not play with me any more. Nobody in school wants to speak with me. I have not spoken to anyone for a long time because no one will listen to me... I wanted to speak with my good friend before, but she is not willing to talk to me at all and always covers her mouth with her hands. Today, I finally found someone I can talk to: the big yellow dog in my family. He is quietly listening when I talk and he will cry when I cry...” (9-years-old girl) (CARN, 2004).

Social withdrawal—“These children have witnessed their parents suffering from the fatal disease. As a result, most of them isolate themselves and do not wish to communicate with others” (Principal of a rural Primary School in Henan; about 30 children in his school have lost one or both parents through AIDS) (China Daily, 2004).

Hatred—“some of the children bear a deep hatred towards society as a result [of their parents’ death]” (worker from the China Population Welfare Foundation) (China Daily, 2004).

“I once met an 8-year-old boy in a village who swore to kill the man who tempted his father to sell blood” (local AIDS Activist) (Gao, 2003).

A boy lost five members of his family to AIDS. The boy quit school in the summer 2002 when he was in the fifth grade. He is working in a brick factory for 10 Yuan [US\$1.2] a day. After paying tribute to his parents’ graves, he carved three Chinese characters signifying “endurance”, “hatred”, and “kill” on his left arm (Shenzhen Daily, 2003).

Hopelessness—“Future? I don’t know what their future will be when I die. My parents are also sick. The kids have AIDS, and the public orphanages won’t take them in. Other relatives have healthy children, and they won’t accept them either. I only hope the government will find a way to help”. (An HIV-infected man whose wife died of AIDS two years ago and his parents and two of his three children were all infected) (CCTV, 2004a).

Hidden feelings—Nine-year old Kong Jeanie in an orphanage always has a smile on her face. But she is not willing to talk about her parents. She said “My brother and I do not want to talk about our mom and dad. If we do, it makes us sad” (CCTV, 2004a).

Discussion

The literature and data presented in this report suggest that AIDS orphans in China were living in a stressful environment. Many orphans were struggling with psychological problems and unmet basic needs such as food, shelter, education, and medical care. Experiences from African countries suggest that although the extended family might alleviate orphans' plight, it is unrealistic to assume that the children can escape from poverty without massive support from external sources (Bhargava & Bigombe, 2003). Relevant government agencies should develop a realistic and sustainable approach to ensure that the children's basic needs are met. National and international agencies should be approached to raise funds for orphans' education and vocational training. More importantly, orphans are strongly stigmatized and suffer from complicated grief resolution and other psychological problems. It is, therefore, essential to provide orphans and their caregivers with mental health services, including bereavement and grief counseling, transitional services, and psychosocial support. Public health workers, school teachers, and community leaders in those areas should be trained such that they can provide basic psychosocial support and referral service to orphans in need.

There are several potential limitations in this review. First, this is a narrative review with limited literature and data and some of the analyses were based on anecdotal reports. Second, no data were available and therefore no comparisons were made with non-AIDS Chinese orphans. Finally, because of the limited empirical data available, no statistical analysis could be performed to synthesize the results.

Future studies should collect data to inform appropriate cultural adaptation of theory-driven behavioral intervention programs among AIDS orphans. Several theory-based behavioral intervention programs among bereaved children in the United States have demonstrated efficacy in improving coping with bereavement-related stressors among orphans (Pfeffer, Jiang, Kakuma, Hwang, & Metsch, 2002; Sandler, et al., 2003) and among children affected by HIV (Forehand et al., 1998; Rotheram-Borus, Murphy, Drainin, & Miller, 1997). Given the resources required for designing and evaluating such effective programs and urgent needs for these programs in China and other resource-poor countries, a plausible and cost-effective approach may be to culturally adapt some of these intervention approaches to new settings. However, there are insufficient data to guide the cultural adaptation and provision of effective intervention to AIDS orphans in China because very limited data are available regarding their mental health status, social and cultural context of their living, and potential mediators and moderators of their psychological well-being.

Future studies should be based on a sufficient sample size, ideally, with a socio-demographically matched comparison group. As noted in the literature above, our understanding as to why some children experience complicated bereavement while others seem to adjust over time has been limited in part because of the small sample size or lack of appropriate comparison group in most of the prior research.

As the Chinese government has promoted the institutionalized care of AIDS orphans, more studies are required to assess the effects of care arrangements on children by assessing the quality of care across multiple care settings in China. The effect of quality of care or care settings need to be examined across developmental stages since the majority of the existing studies of children living in orphanages have mainly focused on early childhood (Chisholm, 1998; O'Connor, Rutter, Beckett, Keaveny, & Kreppner, 2000);

Finally, more exploration is required regarding risk and resilience factors, both individual and contextual, affecting psychosocial functioning, which will inform not only future intervention efforts, but also public policy regarding the care of AIDS orphans in China and other resource-poor countries faced with caring for large numbers of AIDS orphans. By identifying those contextual factors that promote resilience in foster and institutional settings, future studies may develop standards of care for AIDS orphans who are placed outside the family. Furthermore, given the large number of orphans and potential orphans in China and worldwide, future studies should assess the appropriateness of various Western models of grief and bereavement and developmental psychopathology (concepts, measurements, and potential interventions) to other cultures and to adapt or develop appropriate screening tool to identify those children who are in need of immediate and intensive intervention.

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