

CONVENTION ON THE RIGHTS OF THE CHILD (CRC)

Table of specific articles of the CRC (Part I) in relation to Sickle Cell Disease (SCD)

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<p>1. Child defined as under 18, unless majority is attained earlier</p>	<p>Young people over 18 with SCD must rely on other less comprehensive human rights laws. Some countries have a lower age of majority (i.e. being considered as an adult) and this may limit the rights of older adolescents since they are not covered by the CRC there.</p>
<p>2. Non-discrimination on any grounds whatsoever, including race, gender and the status of the child's parent's, family or guardians.</p>	<p>This applies to all children diagnosed with SCD, regarding their access to healthcare services, education, leisure services etc Non-discrimination is key to the planning and implementation of health programmes and community services especially in Africa where SCD is most common. Children with SCD should have support to gain a good education despite periods of illness and possible complications from the disease. Institutions and society as a whole need to counteract elements of stigmatization to allow children with SCD to live a full life despite their diagnosis.</p>
<p>3. Best interests of the child shall be a primary consideration. - State obligation to ensure protection and care as is necessary to a child's wellbeing. - State obligation to ensure quality of institutions, services and facilities for children.</p>	<p>Programmes and services for children with SCD need to be child-centred, child appropriate and child-friendly. The convenience of staff and other adults in healthcare and educational institutions that serve children should not be valued over the best interests of and appropriateness for children of these services. This principle is very useful as a deciding factor in balancing various rights against each other.</p>
<p>4. State's obligation to implement the CRC. Economic, social and cultural rights are to be implemented to the maximum extent of available resources and within the framework of</p>	<p>This is particularly relevant to budgeting of state resources and planning essential services. Poverty and strain on resources makes this a difficult one but the economic, social and cultural rights of children with SCD must not be sacrificed for these reasons. These rights must be implemented to the maximum possible using available resources, charitable and international aid.</p>

international cooperation.	
5. Evolving capacities of the child	The ability for children to engage with issues and make decisions increases as they get older. Service providers must take this into account and involve children in decision making and planning of services. Programmes should be adapted depending on the age-group targeted so that they remain accessible and beneficial for children with SCD of all ages.
6. Right to life -Right to survival and development to the maximum extent possible	States must do everything possible to combat avoidable deaths and disability from SCD. Provision of prompt treatment, prophylactic antibiotics, analgesia, access to hospitals, education etc are important factors in promoting life and development for children with SCD.
7. Right to birth registration, nationality and to know and be cared for by parents as much as possible.	Children's access to services in some countries can be affected if their birth is not registered. Registration of births, especially for a genetic condition like SCD, is important for data collection and statistics which feed into wider programmes that benefit children with SCD. Registration of birth also gives children nationality and identity as well as defining parental responsibility for children with SCD. Providing financial aid and support for parents to care for children with increased healthcare needs due to SCD will help reduce abandonment and stigma .
8. Preservation of identity, nationality, name and family relations	Children with SCD should have equal rights to family relations and identity. This article has implications for inheritance rights and access to services. They should not be overlooked or abandoned due to their condition or possible prognosis.
9. Separation from parents only when in the best interests of the child.	Children with SCD should not be separated from their parents forcibly for any reason including provision of healthcare and state interventions. For example, hospitals should allow children with SCD contact with their parents even while on admission, unless it is in their best interest not to do so.
10. Freedom of movement	Children with SCD should not be restricted because of their diagnosis. They should be free to participate in activities, travel and play, unless it is in their best interest not to do so at the time.

<p>11. Combating the illicit transfer and non-return of children abroad</p>	<p>This applies in relation to orphan children or those who may be sent away by their families.</p>
<p>12. Right to express views freely, given due weight according to child's age and maturity. - Right to be heard in judicial and administrative proceedings</p>	<p>This article is essential for developing programmes and policies that are effective. Children with SCD should be listened to especially when decisions are being made about their future and care, with appropriate consideration given to the child's level of maturity and capacity. Child participation should not be used in an exploitative way or without the child's informed consent.</p>
<p>13. Freedom of expression and the right to seek, impart and receive information, subject to restriction only with regard to respect for others' rights, for national security and public order, health or morals.</p>	<p>This is important for children's access to information about SCD and their participation in sharing such information for public education. A better awareness of the condition by the child and his/her contacts will improve attitudes to children with SCD and lead to better management of the condition.</p>
<p>14. Freedom of thought, conscience and religion</p>	<p>Children with SCD have a right to think for themselves and express their views freely. This links to articles 12 and 13.</p>
<p>15. Freedom of association and peaceful assembly</p>	<p>Children with SCD have the right to meet together to discuss SCD-related issues, share information and organise campaigns. This is only restricted with regard to respect for others' rights, public order, national security, health and morals.</p>
<p>16. Right to privacy, family, home, correspondence, honour and reputation.</p>	<p>A diagnosis of SCD is not an excuse for interfering with a child's privacy and reputation. This includes the right to confidentiality from healthcare professionals, protection of their dignity during examinations and consultations, use of their images and data in campaigns or reports only with valid consent from the child. This right to privacy however must be weighed up against other rights. the rights of others and general public health concerns where relevant.</p>

<p>17. Access to media information from a diversity of national and international sources, especially those aimed at the promotion of social, spiritual and moral wellbeing and physical and mental health.</p> <p>State obligation is to:</p> <ul style="list-style-type: none"> - Encourage dissemination of beneficial information - encourage international cooperation - encourage the production and dissemination of children's books - pay attention to indigenous and minority languages - protect children from information injurious to their well-being 	<p>This article emphasises the need for states to be proactive in programmes for children with SCD. Correct information about SCD should be made available to children and parents in suitable formats, relevant languages and from a variety of sources. Children should be protected from wrong information and misinformation campaigns. Information appropriate for every stage of childhood should be made available to children with SCD in an accessible way e.g. through children's books leaflets and television programmes.</p>
<p>18. Parental responsibility for children, State assistance to families and the development of institutions, facilities and services for the care of children. Childcare services for working parents.</p>	<p>This refers to provision of State support for families affected by SCD where possible. Orphan children and those whose parents are unable to provide the level of care sometimes required should benefit from child care services and institutions.</p>
<p>19. Protection from violence, neglect, maltreatment or exploitation including sexual abuse. State obligation to provide</p>	<p>There should be public awareness campaigns challenging child abuse, violence to weaker/smaller children, bullying in schools and exploitation by others. This should be backed up by effective prosecution and punishment of offenders.</p>

<p>social support programmes and prevention, as well as identification, reporting, referral, investigation, treatment and follow-up of instances of child maltreatment.</p>	
<p>20. Children deprived of a family environment and entitled to special protection and assistance by the state and provision of alternative care.</p>	<p>As extended families are increasingly becoming overburdened by caring for children who do not have parental care, alternative care arrangements should be made by the State. This should be provided with maximum consideration for the child's rights and needs. Institutionalisation should be a last resort only as this may impinge on other rights of the child.</p>
<p>21. Regulations concerning the adoption of children, with emphasis on the best interest of the child.</p>	<p>Adoption may be a way of providing alternative care for children with SCD but this must be carefully regulated to prevent exploitation and abuse. Adoption should be arranged only in the best interest of the child, and children with SCD should not be discriminated against for their condition.</p>
<p>22. Refugee children or children seeking refugee status, whether accompanied or unaccompanied, shall receive appropriate protection and assistance.</p>	<p>This relates to article 2 (non-discrimination) whether or not the child holds the State's nationality. They should receive appropriate protection from violence and exploitation.</p>
<p>23. Rights of children with disabilities. Emphasis on active participation and access to services.</p>	<p>Some children with SCD may have physical or mental disabilities from complications e.g. stroke and infections. Also children with SCD may suffer additional discrimination if they have other unrelated disabilities. The disabilities may put them at higher risk of abuse and exploitation. These children should be protected and access to services should be maximised.</p>
<p>24. Right to the highest attainable standard of health. - facilities for the treatment of illness and for rehabilitation</p>	<p>SCD is not just about physical health - patients need to receive holistic care and counselling when needed.</p> <p>Children have a right to early diagnosis and prompt treatments to prevent mortality and complications which may lead to disability.</p>

<ul style="list-style-type: none"> - State obligation to diminish infant and child mortality - Provision of healthcare to all - combat disease and malnutrition - ensure appropriate pre- and postnatal care for mothers - Access to education and information, support and basic knowledge of child health and nutrition, advantages of breastfeeding, hygiene and sanitation and prevention of accidents. - Develop preventative healthcare, guidance for parents and family planning education and services. - Measures to abolish harmful traditional practices -Emphasis on international cooperation 	<p>Good nutrition and vitamin supplements help promote good health and should be a priority of State programmes for SCD.</p> <p>Good postnatal care should include newborn screening especially in populations where SCD is common.</p> <p>Harmful traditional practices and discrimination based on SCD diagnosis should be targeted using education and provision of informations. Families should be educated about possible triggers for SCD crises e.g. dehydration and infection. Prevention of infection and family planning advice will go a long way in reducing the financial impact of SCD on families.</p> <p>Premarital genetic counselling and prenatal screening may also be offered as part of State programmes with international cooperation if possible, to prevent complications and late diagnosis.</p>
<p>25. Periodic review of placements of children separated from parents</p>	<p>This is potentially relevant for abandoned or orphaned children with SCD.</p>
<p>26. Right of every child to benefit from social security</p>	<p>Children with SCD should not be excluded from State programmes and benefits.</p>
<p>27. Adequate standard of living for physical, mental, spiritual, moral and social development.</p>	<p>There are possible links between poverty and negative attitudes to SCD especially in a healthcare system that is not free for children with chronic conditions. Parents/guidance may feel that children with SCD are a drain on finances and may need State assistance to cope with healthcare costs.</p>

<ul style="list-style-type: none"> - Primary responsibility lies with parents/guardians - State assistance to parents – both material and support programmes, especially with regard to nutrition, clothing and housing. - Recovery of maintenance payments for those financially responsible for the child 	<p>States can provide low cost or free healthcare for children with SCD to reduce this burden. Conditions of poverty such as malnutrition, poor sanitation, lack of medication can lead to increased vulnerability to infection and complications in SCD.</p>
<p>28. Provision of education based on non-discrimination.</p> <ul style="list-style-type: none"> - Compulsory, free, primary education available to all. - Development of different forms of secondary and vocational training with a view to it being free / financial assistance available. - Availability of higher education based on capacity. - Educational and vocational information and guidance available. - Discipline with emphasis on the child's dignity and consistent with the other provisions of the CRC. - International cooperation 	<p>Children with SCD should have access to education and there should be room for adjustments to be made to allow for them to continue schooling as much as possible, even after periods of illness or hospital admission. Children with SCD can even be encouraged to take part in learning activities while in hospital if possible, so that they do not fall far behind and suffer discrimination among their peers. Careers counselling should be offered early with a positive attitude to children with SCD so that children can be aware of what careers are open to them and which are not advised, if any.</p> <p>There is a need to assess, manage and mitigate the impact of SCD on education and promote factors and environments that are inclusive and strengthen the capacity of educational systems to cater for all children. Discipline should be considerate of the child's dignity and rights.</p>
<p>29. Aims of education.</p>	<p>Children with SCD should be encouraged to reach their fullest potential in preparation for a responsible adult life in a free society. Vocational skills and non-formal education should be offered as options</p>

<p>- Development of child to his/her fullest potential</p> <ul style="list-style-type: none"> - Development of respect for human rights - Respect for cultural identity, national values and other civilisations. - 'The preparation of the child for responsible life in a free society, in the spirit of understanding, peace, tolerance, equality of sexes, and friendship among all peoples, ethnic, national and religious groups and persons of indigenous origin'. - Respect for the natural environment - Conformity of educational institutions to the minimum standards established by the State. 	<p>without discrimination. Children should understand their condition and rights as humans.</p>
<p>30. Rights of minority and indigenous children to enjoy their culture, religion and language.</p>	<p>Information materials about SCD should be provided in various languages and should be culturally sensitive. Minority tribes must not be excluded from information provision and State programmes.</p>
<p>31. Right to rest, leisure, play and participation in cultural life and the arts. State provision for such opportunities.</p>	<p>Children's involvement in SCD programmes e.g. through creative arts, can be effective in individual development and peer education. The state should provide such programmes to provide safe leisure activities, interaction and play for children with SCD.</p>
<p>32. Protection from economic exploitation/</p>	<p>The economic and financial pressures placed on households due to SCD related healthcare costs may create an environment where children may be</p>

<p>hazardous work / work that interferes with education.</p> <ul style="list-style-type: none"> - State provision of measures, including education, to ensure this. - Provision of minimum age for employment - Regulation of hours and conditions of employment 	<p>exposed to child labour and risky situations. Children should be protected from work that renders them vulnerable to abuse and exploitation.</p>
<p>33. Protection from illicit use and from the production and trafficking of narcotic drugs and psychotropic substances.</p>	<p>Substance abuse may begin as a quest for pain relief and escapism. This increases the risk of potential sexual abuse and exploitation e.g. sex in exchange for drugs and money. Children with SCD should be protected from drug addiction and opiod abuse.</p>
<p>34. Protection from sexual exploitation and abuse.</p> <ul style="list-style-type: none"> - States must take measures to prevent the inducement or coercion of children into unlawful sexual activity and the exploitative use of children in prostitution and pornography. 	<p>Sexual abuse and exploitation can increase the risk of infections such as HIV, thereby worsening the outcome for SCD. States must prevent the coercion of children into unlawful sexual activity and risky healthy behaviours.</p>
<p>35. Prevention of abduction, sale or trafficking of children for any purpose in any form.</p>	<p>Children with SCD need to be protected under several articles of the CRC from trafficking and abduction.</p>
<p>36. Protection from all other forms of exploitation prejudicial to any aspect of the child's welfare.</p>	<p>Children with SCD also have a right not to be exploited in any other way.</p>
<p>37. Freedom from torture, cruel,</p>	<p>Children with SCD may be subjected to degrading treatment due to discrimination or ignorance. This</p>

<p>inhuman or degrading punishment or treatment.</p> <ul style="list-style-type: none"> - No capital punishment or life imprisonment without possibility of release. - No arbitrary or unlawful deprivation of liberty. Detention as a last resort, for the shortest time possible. - Humanity and dignity for children deprived of their liberty. - Right not to be detained with adults. - Right to maintain contact with family. - Prompt access to legal assistance. 	<p>worsens their vulnerability to infection, low self esteem and complications.</p> <p>Detention, even for health reasons, e.g. admission to hospital should be for the shortest time possible and contact with family should be maintained. Children with SCD also have the right not to be detained with adults and to have their dignity upheld even in detention. There must be a clear emphasis on alternatives to detention and legal assistance should be provided promptly by the State.</p>
<p>38. Children and armed conflict.</p> <ul style="list-style-type: none"> - Sets 15 as the minimum age for recruitment and direct engagement in hostilities. - Protection of civilian populations in armed conflict. - Protection and care of children affected by armed conflict. 	<p>Access to healthcare services may be severely disrupted in times of armed conflict. Children may also be at risk of rape, forced marriages etc, thereby increasing their risk of infection and mortality. Prevention programmes should be targeted at adult soldiers.</p>
<p>39. Promotion of physical and psychological recovery and social reintegration of child victims of : neglect, exploitation, abuse; torture, cruel, inhuman or degrading treatment or punishment; or</p>	<p>Emphasis on holistic approach to care.</p>

<p>armed conflict. Emphasis on health, self-respect and dignity of the child.</p>	
<p>40. Juvenile justice / children in conflict with the law. - Emphasis on dignity and reintegration - Right to legal guarantees and due process - Establishment of minimum age of criminal responsibility. - Educational and vocational training programmes and alternatives to detention.</p>	<p>Children with SCD also have the right not to be detained with adults and to have their dignity upheld even in detention. There must be a clear emphasis on alternatives to detention and legal assistance should be provided promptly by the State.</p>
<p>41. In the case of other domestic or international legislation on any of the CRC provisions, the higher standard shall always apply.</p>	

Reference:

Convention on the Rights of the Child: Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989, entry into force 2 September 1990, in accordance with article 49

UNICEF FACT SHEET: A summary of the rights under the Convention on the Rights of the Child