SICKLE CELL IN SCHOOLS: A Guide to School Policy

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BARKA!
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Introduction

• Here is a quick overview of how we devised a guide to school policy for young people with sickle cell disease.

• With newborn screening for sickle cell, the majority of young people with sickle cell disease can live to school age and into adulthood. Our concern was that the gains made by newborn screening might be lost if young people with sickle cell disease did not get the right support at school.
The Research

In the project, 569 young people with sickle cell disease aged 4-25 years shared their school experiences.
Absences from School

• 17 days each school year on average
• Absences typically in blocks of 2, 3 or 5 days
• Reported that they were not helped that much to catch up lessons missed.
Reported Experiences in Schools

Number of children questioned

<table>
<thead>
<tr>
<th>Experience</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Allowed Toilet</td>
<td>46%</td>
</tr>
<tr>
<td>Not Allowed Drink</td>
<td>36%</td>
</tr>
<tr>
<td>Unsuitable Exercise</td>
<td>34%</td>
</tr>
<tr>
<td>Called Lazy When Tired</td>
<td>57%</td>
</tr>
</tbody>
</table>
Raising Teacher Awareness Is Not Enough!

• Even where teachers were given information about sickle cell disease this did not overall improve support to young people with SCD.

• Young people with sickle cell disease did not like anything that marked them out as different. They wanted to be like their peers.
Policy

From this project we have made a guide for schools.

It has been translated into several languages including Nigerian.

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Nigeria Versions

• Reviewed by Bola Ojo, Naomi Maiguwa, Jonah Lah, Dr Baba Inusa, Comfort Okolo and Elizabeth Anionwu.
• Inserted good practice examples from Nigerian schools (e.g. on malarial environmental clear-ups and on building schools on one level)
• Translated into Hausa, Yoruba and Igbo
Policy - the Hausa version!
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