



# SICKLE CELL IN SCHOOLS: A Guide to School Policy

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**BARKA!**

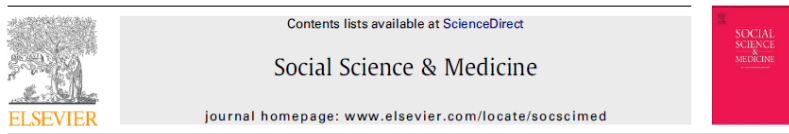
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# Introduction

- 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.



Disclosure and sickle cell disorder: A mixed methods study of the young person with sickle cell at school

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## ABSTRACT

Sickle cell is a leading genetic condition, both globally and in England. Little research has been conducted into the experiences of young people with sickle cell at school. A mixed methods study (May 2007–September 2008) based on 569 questionnaires and 40 taped interviews with young people living with sickle cell disorder (SCD) in England found that students with SCD are faced with a dilemma as to whether or not to disclose their sickle cell to teachers and pupils; the latent and hidden characteristics of their symptoms make it possible, in Goffman's terms, to "pass". However the variable and unpredictable course of sickle cell is a reminder of Goffman's notion of being "discreditable". We found that teacher or pupil knowledge that a young person has sickle cell is not statistically associated with reported better treatment of young people with SCD at school. Analysis of interviews suggests most young people favour disclosing their sickle cell status (on the basis that teachers will then know what actions to take in the face of bouts of illness and in terms of making allowances for illness or school absences). A minority disagreed because disclosure was felt to attract unwarranted attention or disabling attitudes. Attitudes to disclosing to peers were more varied: either for or against disclosure to peers, or ambivalent in that they felt a tension between acknowledging the reality of their sickle cell, and not

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**Sickle cell, habitual dys-positions and fragile dispositions: young people with sickle cell at school**

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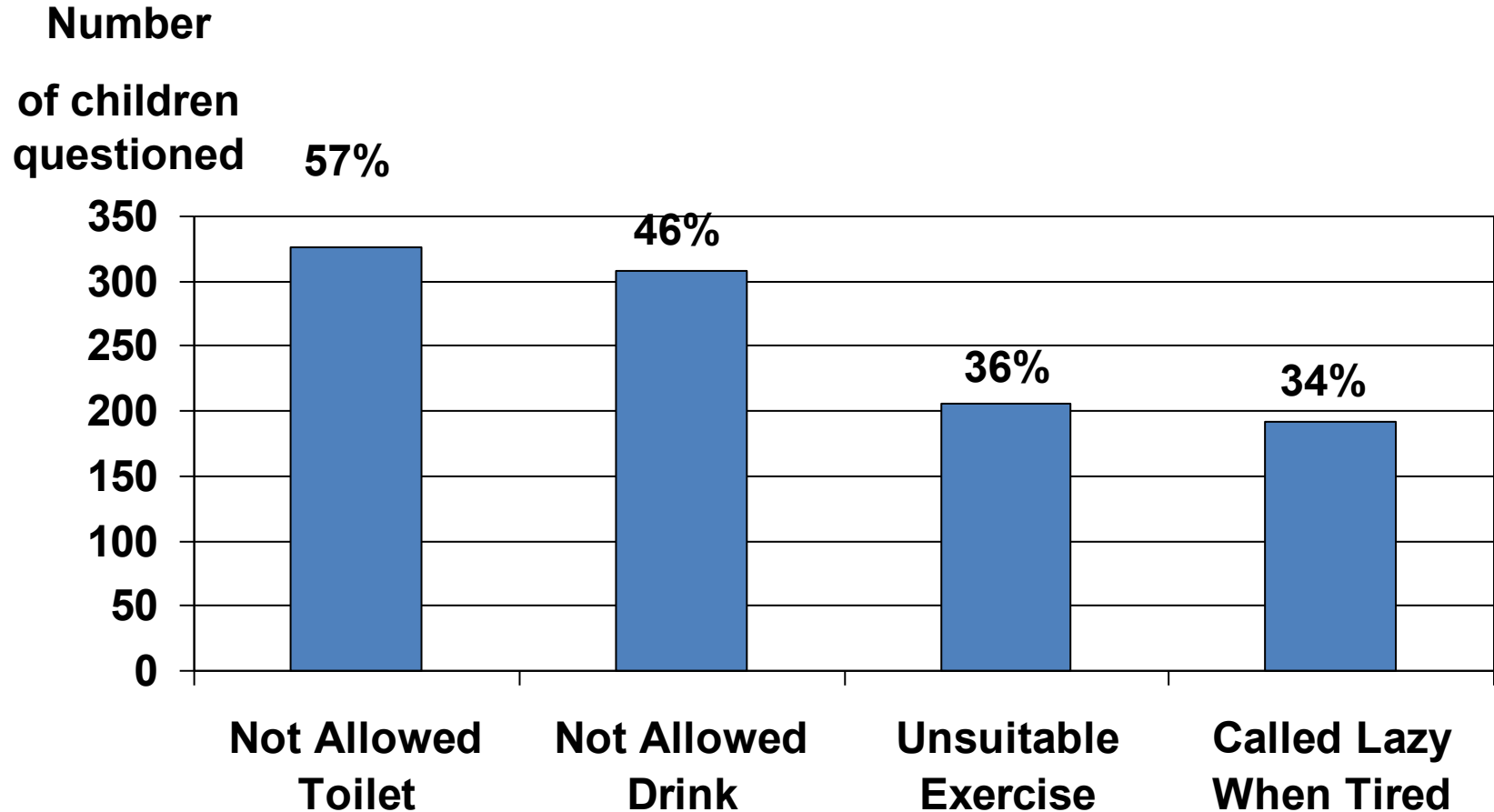
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# Absences from School

- 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



# 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.

It is an open education resources – licensed by Creative Commons – meaning anyone can adapt and use it without charge.



# Sickle Cell and Thalassaemia:

SCHOOL

*Health and Safety*

SCHOOL

A Guide to School Policy



# 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!



# Ciwon Sikila

Bayanai Don Najeriya

*Makarantar firamare*

*Lafiya da Kariya*

*Makarantar sakandare*

Jagora Ga Makaranta

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# More Open Educational Materials

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