



# SUPPORTING STUDENTS WITH SICKLE CELL: PART II

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# THE AGENDA



Closing the gap



Current Progress  
and Supports



Recommendations  
from Sickle Cell  
families



My Personal  
Recommendations

# QUESTIONS I AM LEFT WITH AFTER RESEARCH AND INTERVIEWS



What can the system do?



What can be done without direct services from an IEP?



What do SCD children and families want to see?



What can OT's do?

## THE GAP

There is a need for increased support for students with sickle cell in the school system. More specifically, there is a need for supports in the classroom, the school building, providing family education, and with collaboration with school personnel.



## CURRENT SUPPORTS FOR SICKLE CELL RESEARCH

- Cincinnati Children's hospital is exploring the academic concerns of students with SCD compared to their school service utilization.
- Within this research they are incorporating data from the Brief School Needs Inventory (Elam et al., 2019) to broaden their view of children's academic challenges.
- Their findings on SCD student retention, lower test scores due to increased strokes, and racial barriers emphasize the need for improved supports and advocacy for this population in the school system



# CURRENT SUPPORTS FOR SICKLE CELL STATES AND SCHOOL DISTRICTS

- Sickle Cell Handbooks developed by:
  - Statewide manuals, district manuals, CDC manuals, etc.
- Sickle Cell Centers dedicated to supporting children and families of sickle cell through navigating health, school, and community services
  - Advocacy
  - Mental health supports
  - Community resources and supports

# RECOMMENDATIONS FROM A SICKLE CELL SURVIVOR

## **What is something that you wish you had as a child with sickle cell?**

- A Support Program through school, not just the sickle cell center
- “I Needed more support during crisis, time extensions, comfort, medication management”
- “I wish that I had a space in school to deal with my crisis, since leaving school early can be complicated and disruptive”

## **Is there anything you would like other children, families, or teachers to know?**

- “There needs to be a teacher support program to educate teachers on the diseases so that they can understand us”
- “Teaching others is a good thing for them to know how to react to you”
- *Support and advocacy are key elements for success*

# RECOMMENDATIONS FROM A SICKLE CELL PARENT

## **What advice would you give to other sickle cell parents navigating the school system?**

- “You are your child's #1 advocate”
- “You have to understand what your kid needs, and everyone needs to know how to communicate it”

## **When did you find out about sickle cell?**

- “I didn’t find out about it until my child had it”
- The familial unit was her first point of reference for education and understanding

## **What is piece of advice you would give your younger self?**

- “Don’t be afraid of the unknown”
- Learn more information on how to support your child and do not inhibit them if it is not necessary.

## **What do you wish that the school system could have offered her?**

- Support groups , sickle cell or any chronic conditions. Something to help with stigmas and the feelings of missing out





# WHAT CAN OCCUPATIONAL THERAPY DO?

## Consults

- Although OT's may not work directly with children with sickle cell, they may still serve as a consult where they can make suggestions for the child and their family
- Suggestions for mental health outlets and coping

## Educational Handouts

- Locate or develop educational information for students, families, school personnel, and the school community members
- Provide families with handouts on energy conservation, pain management, or regulation strategies



# WHAT CAN OCCUPATIONAL THERAPY DO?

## Direct Education

- Collaborating with school personnel to present information to families on Section 504 plans, outlining student and family rights, and emphasizing the importance of school accommodations.

## Advocacy

- Be an advocate for families
- Be their liaison into utilizing specialized services
- Share information on sickle cell disease
- Support students and families as they advocate for themselves
- Program Development

# THANK YOU

Please reach out me at [Siarah.Jones@tufts.edu](mailto:Siarah.Jones@tufts.edu)  
with any questions!

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