

Disparities in School Supports for Patients with Sickle Cell Disease and Cystic Fibrosis

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Background

- Sickle cell disease (SCD) and cystic fibrosis (CF) are genetic conditions that present at birth with lifelong needs.

	SCD	CF
Frequency	100,000 people in US	35,000 people in US
Demographics	Predominantly Black or Hispanic/Latinx	Predominantly non-Hispanic/Latinx whites
Complications	Anemia, pain crises, acute chest syndrome, stroke, asplenia	Frequent lung infections and poor growth/weight gain.
Management	Medication (hydroxyurea), annual screening transcranial doppler, pain management	Pancreatic enzymes, antibiotic regimens, chest physiotherapy
Cognitive Impact	Overt strokes/silent cerebral infarcts can lead to decline in cognitive function	No known direct cognitive effects

- Children with chronic health care needs may need school supports due to impacts of disease, absenteeism, etc.
- School supports and services may be provided through an Individualized Education Program (IEP) or Section 504 Accommodation Plan (504 Plan).
- Multiple disparities exist for minority children vs. white peers:
 - In medical outcomes with increased morbidity/mortality and inequitable treatment access in various diagnoses.
 - In socioeconomic status with black children more often living in poverty.
 - In educational outcomes and access.
 - In expulsion and suspension from school, occurring at much higher rates for black children, higher risk of drop-out/non-completion of high school. This is part of the “school-to-prison pipeline.”

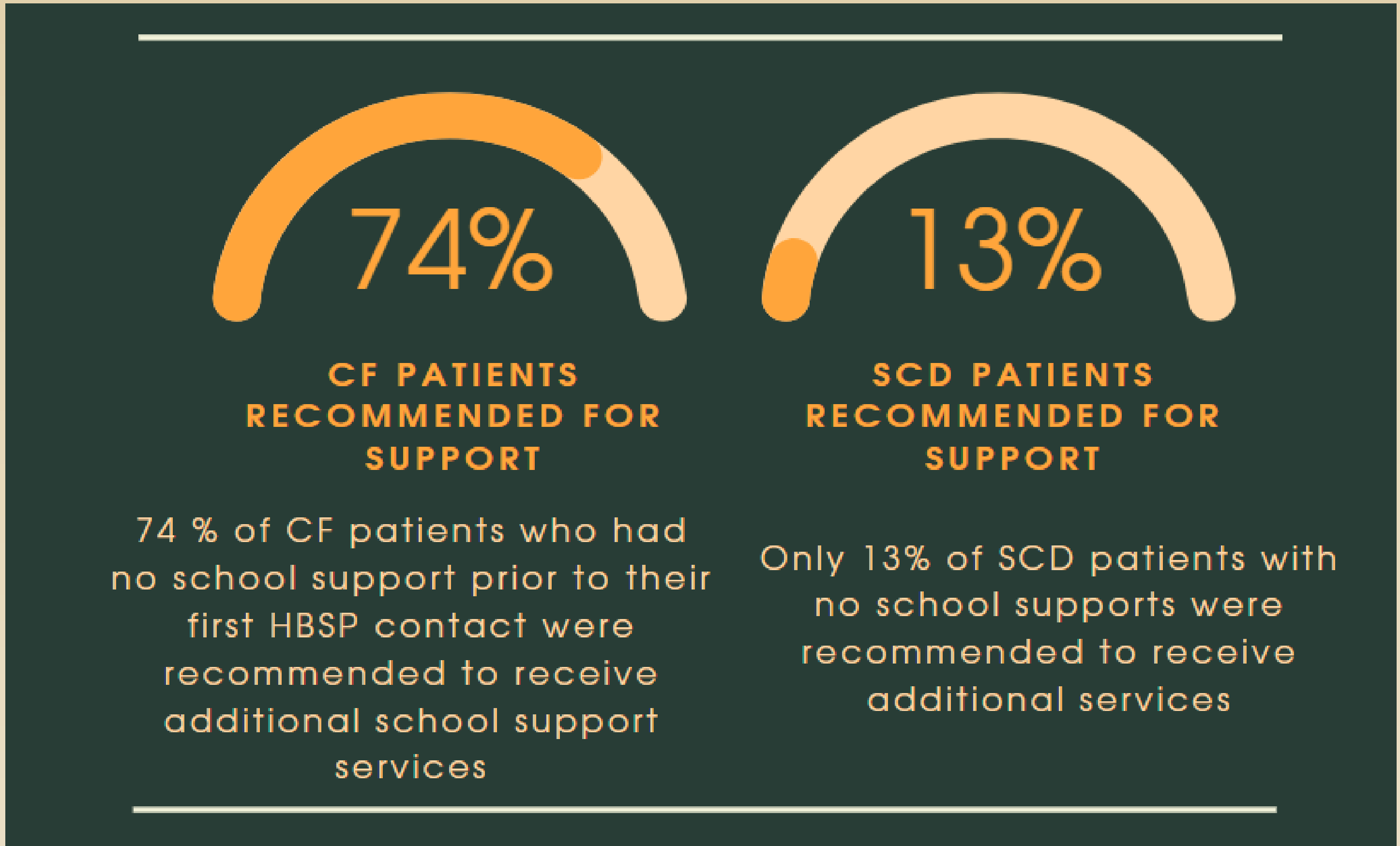
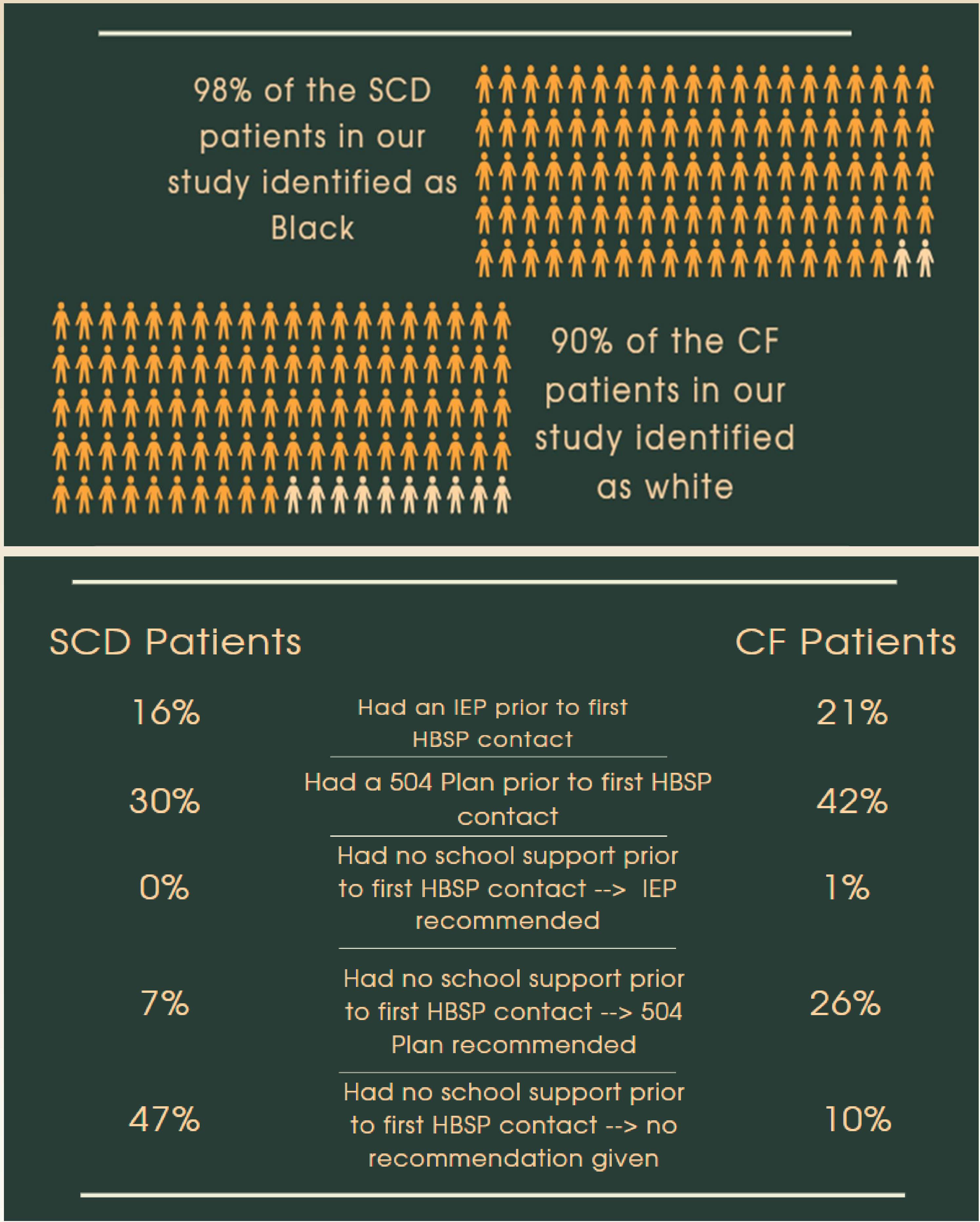
Objective

Given disparities in medical and educational services, our study aimed to compare the current school supports in place and recommended supports for students with SCD and CF

Methods

- Data were collected from a hospital-based school program (HBSP) at a large academic medical center. Sample size:
 - 43 unique SCD patients** with 78 encounters
 - 104 CF patients** with 178 encounters.
- Data were cleaned by one rater; 30% reviewed for interrater reliability.
- Discrepancies were resolved with the research team.
- Data were analyzed through descriptive statistics in Microsoft Excel.

Results



Conclusions

- Given the impact of diseases such as SCD and CF, many patients with those diseases would qualify for school supports. However, individuals with SCD are at risk of cognitive impacts secondary to infarct/stroke with need for more extensive supports compared to those with CF.
- In this study, we found disparities between SCD patients vs. CF patients in percentage of:
 - Patients with an IEP or 504 Plan prior to first HBSP contact
 - Patients recommended to receive school supports after HBSP contact
 - Patients having existing IEP or recommended for an IEP
- The discrepancies in the recommended school supports for children with CF and SCD are concerning and further contribute to educational disparities.

Future Directions: Improving support for children with SCD through HBSP education, material development regarding disease education for teachers/ peers, development of comprehensive recommendations of school support needs for children with SCD, etc.

References

