Supporting Families of Children with Sickle Cell Anemia

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K-12 Education for Children with Sickle Cell Anemia

- **Individuals with Disabilities Education Act 2004**
  - Students eligible for special education services under Section IDEA must
    - Meet criteria in statute to be considered a child with a disability
    - Sickle cell anemia specifically mentioned as a chronic condition under the eligibility category of “other health impairment”

- **Section 504 of the Rehabilitation Act of 1973**
  - Students eligible for accommodations and services under Section 504 must
    - have a physical or mental impairment that substantially limits one or more major life activities; or
    - have a record of such an impairment; or
    - be regarded as having such an impairment

- Focus on providing a free appropriate public education (FAPE)
Higher Education and Young Adults with Sickle Cell Anemia

- Section 504 and the Americans with Disabilities Act (ADA) apply to post-secondary education
- Post-secondary institutions must provide appropriate academic adjustments as necessary to ensure that it does not discriminate on the basis of disability
- Focus in post-secondary institutions is on access, not FAPE
- Students must request academic adjustments and follow institution’s policies and procedures
- Institutions must identify staff responsible for ensuring compliance with Section 504 and ADA
Helping Families and Youth Navigate Systems

- IDEA provides funding to States to provide special education services.
- IDEA also provides discretionary funding to States, institutions of higher education, and non-profits to support the provision of special education services.
- IDEA institutes a system of parent training and information centers and community parent resource centers (collectively “parent centers”) to help families navigate systems.
- IDEA also institutes parent technical assistance centers to support parent centers in doing their job, which includes a national Center for Parent Information and Resources (CPIR).
Parent Training and Information Centers & Community Parent Resource Centers

- Provide training and assistance to help parents:
  - Understand their children’s disabilities and their educational needs
  - Understand their rights and responsibilities under IDEA
  - Communicate effectively and work collaboratively with educators
  - Participate in their children’s education
  - Resolve disputes with schools
  - Participate in activities at the school level that benefit their children
  - Participate in school reform activities

- Variety of services including one-on-one assistance, workshops, publications, and Web sites

(IDEA Sec. 671, (b) )
Supporting the Parent Centers Who Serve Families of Children with Disabilities

FEATED RESOURCE

Practice Guides for Families

FEATED PARENT CENTER

Raising Special Kids – Online Parent Trainings
Raising Special Kids, Arizona’s Parent Training and Information Center, offers online parent trainings on topics such as "Turning 16 - Legal Options", "Early Intervention 101" and "Ten Things to Know Before Your Next IEP Meeting." Some of the presentations have a focus on Arizona, but in general the topics apply to anyone with a child with a disability. Check out their full list of titles. Don’t forget to scroll to their "Stories" section to hear from families about their experiences.

www.parentcenterhub.org
Family-to-Family Health Information Centers

http://familyvoices.org/ncfpp/f2fs/
Resources

- Protecting Students with Disabilities
  https://www2.ed.gov/about/offices/list/ocr/504faq.html

- Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities
  https://www2.ed.gov/about/offices/list/ocr/transition.html

- CPIR’s Transition to Adulthood Page
  https://www.parentcenterhub.org/transitionadult/

- CPIR’s Fact Sheet on Sickle Cell Anemia
  https://www.parentcenterhub.org/ohi-sicklecell/

- CPIR’s Fact Sheet on Other Health Impairment
  https://www.parentcenterhub.org/ohi/
Thank You!

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