Children’s Rights at Schools

Tariq Ahmad, M.D., F.A.A.P.

Associate Clinical Professor of Pediatrics
Division of Pediatric Endocrinology & Diabetes
UCSF Benioff Children’s Hospital Oakland
March 5, 2017
Objectives

- Know what to expect from your child as they grow
- Know your resources and your rights
- How to work with the schools
- Enjoy this time with them, before you know it, they are off to college!
What can kids do (and what can’t they do)?
Toddler and Early School Age
Toddler and Early School Age

- Developmental tasks
  - Initiating activities
  - Confidence in self
- Lack fine motor control, cognitive development and impulse control
- Appetite and activity unpredictable
- Difficult for parents to share care with others
  - Fear others won’t know what to do
  - Undetected hypoglycemia / brain development
Toddler and Early School Age (cont.)

- **Cannot**
  - Perform diabetes tasks independently
    - Adults must provide all aspects of diabetes care
  - Reliably recognize hypoglycemia
    - School personnel must be trained to recognize

- **Can**
  - Determine which finger to prick
  - Choose an injection site
  - Are generally cooperative
Older School-aged Children
Older School-aged Children

- Developmental tasks
  - Athletic, cognitive, artistic, and social skills
  - Self-esteem and social competence

- Development of normal peer relationships
  - Attend school regularly
  - Participate in school activities and sports
  - Make diabetes regimen flexible
Older School-aged Children (cont.)

- Can begin to assume more of the daily diabetes management tasks
  - Insulin injections
  - Blood glucose testing
  - Bolus with pump for standard carb meals

- Still need significant supervision for management decisions
  - “Shared care” between adult and child
Adolescence
Adolescence

- Have fine motor control to perform most self-management activities
- Still need help with decision-making
- Shared management
  - Improved control
- Parent-child conflict
  - Associated with poorer diabetes outcomes
Developmental Tasks

- Manage rapid biologic changes
- Struggle to find their own identity
- Drive for independence
- Drive for peer acceptance
Challenges

- Increased insulin requirement during puberty
- Blood glucose control becomes more difficult
- Higher incidence of:
  - Depression
  - Generalized anxiety disorders
  - Eating disorders
  - Risky behavior
  - Reduced adherence to the treatment regimen
Non-adherence in Adolescence

- Rebellion
- Experimentation
- Ambivalence
- Impulsiveness
- Mood swings
- Need to be accepted by peers
- Separate from family
- Risk-taking behaviors
- Sense of invulnerability
Improving Adherence
Improving Adherence

- Shared management
  - Parents maintain partnership with adolescents
- Parent-child conflict
  - Poorer diabetes outcomes
- Risk of over- or under-involvement
- Assist with transition to more independent self-management
- Punishment doesn’t seem to work
College
Pearls

- Know where the health center is
- Register with the Disability office
  - Early Registration
  - Priority Housing
  - Exams
- Resident Advisors
- Glucagon
- Being Responsible
What can schools do (and what can’t they do)?
Is this happening to you?

- Child care program doesn’t allow your child to return after being diagnosed
- Your child is not allowed to eat a snack with other children because there is no one to give him insulin
- You have to leave work because no one at the child care program can provide care
Know your team

- Social worker
- CDE/Nurse
- Nutritionist
- Psychologist
- Physician
- Kid and their family
The Law is on your side

- American with Disabilities Act (ADA)
- Section 504 of the Rehabilitation Act (Section 504)
- Individuals with Disabilities Education Act (IDEA)
Americans with Disabilities Act (ADA) of 1990

- Prohibits child care programs, camps, and other child care centers from treating children with disabilities unfairly
  - Disability – a “physical or mental impairment that substantially limits one or more major life activities.”
- Applies to all public (Title II) and private schools (Title III) unless there is a religious affiliation
Section 504 of the Rehabilitation Act of 1973

- Protects your child if the child care program or school receives **federal funding**
- Applicable whether public or private unless the institution is run by a **religious organization**
  - Unless religious organization has federal funds
The Individuals with Disabilities Education Act

- Some children may need an Individualized Education Program (IEP) if there is proof that the student’s disability is harming their ability to learn.
- Federal funding provides the institution to provide such services.
  - So these are usually public education agencies.
Other Local Cali Laws...

- California Health & Safety Code, Div 2.5, Chapter 9, § 102 (2009)
  - Individuals will not be liable for good faith efforts to assist in an emergency
- California Health & Safety Code, Div 12, Chap 1, Article 6, § 101226 (2009)
  - A daycare may administer prescription medication
- California Health & Safety Code, Div 12, Chapter 1, Article 1 California Health & Safety Code, Div 12, Chap 1, Article 6, § 01175(5) (2009)
  - Any child care staff can be designated to administer glucagon or insulin
Initial Steps to take with school

- Inform anti-discrimination personnel, principal, or school nurse
- Provide consent so that they can talk with your medical team
- Provide all the supplies (ie equipment/supplies, snacks, insulin)
- Be a resource (you or your diabetes team can provide training)
- Make sure at least one staff member is trained and available to give insulin or glucagon
- Keep a log of all relevant communications, conversations
- Provide details as to when you want to be called
Can submit a formal request

- School is supposed to initiate the process to provide modifications or accommodations (Section 504 and ADA)
- Purpose of the request
- Limitations caused by the disability
- How the condition will affect the skills and abilities expected of the student – including both life and academic skills and abilities
- The types of accommodations requested
- Provide medical documentation of the disability
- Offer to participate in any needed evaluation or meeting to discuss accommodations
504 Plan

MODEL 504 PLAN FOR A STUDENT WITH DIABETES

[NOTE: This model 504 Plan lists a broad range of services and accommodations that might be needed by a child with diabetes in school. The plan should be individualized to meet the needs, abilities, and medical condition of each student and should include any other items in the model that are relevant to their student. Some students will need additional services and accommodations that have not been included in this model plan.]

Section 504 Plan for ________________

School __________________________

School Year: ______________________

<table>
<thead>
<tr>
<th>Student’s Name</th>
<th>Room #</th>
<th>Grade</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>John Smith</td>
<td>201</td>
<td>6th</td>
<td>Type 1 DM</td>
</tr>
<tr>
<td>Jane Doe</td>
<td>202</td>
<td>7th</td>
<td>Type 2 DM</td>
</tr>
</tbody>
</table>

OBJECTIVES/GOALS OF THIS PLAN

Diabetes can cause blood glucose (sugar) levels to be too high or too low, both of which affect the student’s ability to learn as well as severely endangering the student’s health both immediately and in the long term. The goal of this plan is to provide the special education and related services needed to maintain blood glucose within the student’s target range, and to respond appropriately to levels outside of this range in accordance with the instructions provided by the student’s personal health care team.

REFERENCES

- School accommodations, diabetes care, and other services set out in this Plan will be consistent with the information and protocols contained in the National Diabetes Education Program (NDEP) brochure, “Helping the Student with Diabetes Succeed: A Guide for School Personnel,” June 2010.

DEFINITIONS USED IN THIS PLAN

1. Diabetes Medical Management Plan (DMMP): A plan that describes the diabetes care regimen and identifies the health care needs of a student with diabetes. This plan is developed and approved by the school’s protocol health care team and family. Schools must also include to the parents and child’s health care provider if a DMMP is not submitted by the family. (Note: School districts may have other names for the plan. If so, substitute the appropriate terminology throughout.)

2. Quick Reference Emergency Plan: A plan that provides school personnel with essential information on how to recognize and treat hypoglycemia and hyperglycemia.

3. Trained Diabetes Personnel (TDP): Non-medical school personnel who have been identified by the school nurse, school administrator, and parent who are willing to be trained in basic diabetes knowledge and have received training coordinated by the school nurse in diabetes care, including the performance of blood glucose monitoring, insulin and glucagon administration, recognition and treatment of hypoglycemia and hyperglycemia, and performance of intensive care, and who will perform these diabetes care tasks in the absence of a school nurse.

1. PROVISION OF DIABETES CARE

1.1 At least one staff member will receive training to be a Trained Diabetes Personnel (TDP), and either a school nurse or TDP will be available at all times during school hours, during extracurricular activities, and on school sponsored field trips to provide diabetes care in accordance with this Plan and as directed in the DMMP, including performing or overseeing administration of insulin or other diabetes medications. This includes programming and troubleshooting the student’s insulin pump, blood glucose monitoring, insulin checks, and responding to hypoglycemia and hyperglycemia including administering glucagon.

1.2 Any staff member who is not a TDP and who has primary care for the student at any time during school hours, extracurricular activities, or during field trips shall receive training that will include a general overview of diabetes and typical health care needs of a student with diabetes, recognition of high and low blood glucose levels, and how and when to immediately contact either a school nurse or a TDP.

1.3 Any bus driver who transports the student must be informed of symptoms of high or low blood glucose levels and provided with a copy of the student’s Quick Reference Emergency Plan and be prepared to act in accordance with that Plan.

2. TRAINED DIABETES PERSONNEL

The following school staff members will be trained to become TDPs by __________________ (date)
The power of 504

- Field Trips
- Extra-curricular activities
- Access to food, water restrooms
- How meds will be stored and disposed
- When parent or physician should be contacted
- Evacuation plan
- Who will give glucagon
- Test taking
- No penalties for diabetes related infringements
- Missed classes
- Who is to monitor for symptoms
- Nutrition info provided
- Everyone is different
Teachers

- Should be an advocate
- Should be aware of potential bullying
- Should be aware that exams or speeches may have to be delayed if BG’s are not in target
- Should have a comfortable communication with parents and school nurse
- Should have someone accompany child to restroom or nurse’s office

- Should accommodate “supervising and monitoring...of child” (US vs Rainbow River Child Development Center, 2010)
Tests

- For standardized tests apply even 6 months in advance
  - www.collegeboard.com
  - www.act.org
- Can have more frequent or longer breaks, but not more test taking time
- For school exams can have more accommodations
  - Snacks during test
  - Test during exam
College

- Colleges have no requirement to identify those with a “disability”
- While elementary and secondary schools have to provide “a free and appropriate education” if they receive federal funding, colleges cannot discriminate once a student has “qualified” academically for admission to the school
- Colleges are not required to provide modifications that would impose an undue burden or fundamentally alter a program
- Colleges don’t have to help assist in providing health services
- A formally written 504 plan is not typical, but a documentation of modifications can be provided
Other things to do

- Apply through the disability services office
- Look at the colleges anti-discriminatory policies
- Consider informing roommate, professors, RA
- Consider a plan to take breaks for snacks or checking one’s BG’s
- Consider priority housing and early registration
- Know where the health clinic is or the local ER’s
- Colleges may not do a 504, but rather will provide an “accommodations letter”.
Can submit a formal request to get an “accommodation letter”

- Purpose of the request
- Limitations caused by the disability
- How the condition will affect the skills and abilities expected of the student – including both life and academic skills and abilities
- The types of accommodations requested
- Provide medical documentation of the disability
- Offer to participate in any needed evaluation or meeting to discuss accommodations
What can parents do...

- Help with prescriptions and supplies
- Help with setting up follow up appointments
- Consider getting HbA1c checks locally
- Care packages with carb snacks 😊
Scholarships!

- [https://collegediabetesnetwork.org/content/scholarships](https://collegediabetesnetwork.org/content/scholarships)
  - Diabetes Scholars Foundation Scholarships
  - Novo Nordisk Donnelly Awards
  - Scott and Kim Verplank Foundation
  - Frederick J. Krause Scholarship on Health and Disability
  - Team Type 1 Scholarships
  - Diabetes Incorporated
When there is a problem

- Designated personnel or principal
- Mediation
- Internal school or district grievance procedures
- Impartial hearings
Legal Recourses

- Complaints in re Section 504 and ADA
  - Dept. of Education - Office of Civil Rights (180 day statute aside from waiver) for Section 504
    - Mail, fax, on-line, in person (800-421-3481)
    - www2.ed.gov/about/offices/list/ocr/complaintprocess.html
  - Dept. of Justice for ADA - 800-514-0301 (though for public schools through OCR)
    - http://www.usdoj.gov/crt/ada/t3compfm.htm
  - Impartial hearing at district or state level
    - Applies to IDEA as well
- For IDEA call (916) 263-0880
  - Private lawsuit through state or federal court
Legal Resources

- Disability Rights Education and Defense Fund, Inc. (DREDF)
  - A national law and policy center dedicated to protecting and advocating for the civil rights of people with disabilities
  - Info: 510-644-2555
  - Web: www.dredf.org/diabetes
  - www.diabetes.org (under advocacy)
More Resources…

- Council of Parent Attorneys and Advocates
  - [http://www.copaa.net](http://www.copaa.net)
  - National Disability Rights Network - (202) 408-9514
  - [http://www.ndrn.org](http://www.ndrn.org)

- National Dissemination Center for Children & Youth With Disabilities - 800-695-0285
  - [http://www.nichcy.org](http://www.nichcy.org)
UCSF Benioff
Children’s Hospital Oakland Division
of Endocrinology & Diabetes

- **Diabetes Nurses**
  - Kathy Love (R.D)
  - Barb King-Hooper
  - Lois Carelli
  - Victor Woolworth
  - Rosibel Jones
  - Michelle Roy

- **Endocrine Nurses**
  - Anita Markoff
  - Andrea Pederson

- **Research Nurse**
  - Betty Flores

- **Social Workers**
  - Amy Warner
  - Kristin Avicolli

- **Office Staff**
  - Kim Lawas
  - Juliet Gervacio
  - Sherita Joseph

- **Physicians**
  - Jenny Olson
  - Ivy Aslan
  - Sonali Belapurkar
  - Alison Reed
  - Tariq Ahmad
Thank you for your attention....Questions?