



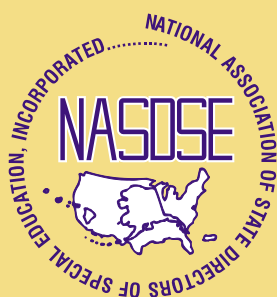
THE HSC HEALTH CARE SYSTEM

The HSC Foundation

Partnering with Your Child's School: A Guide for Parents

Information and Resources for Families
of Children with Health and/or
Mental Health Care Needs

THE GEORGE WASHINGTON UNIVERSITY
GRADUATE SCHOOL OF EDUCATION
AND HUMAN DEVELOPMENT



Introduction

The booklet is designed to help parents of children who have been diagnosed with health or mental health care needs to learn about available resources and to develop a partnership with their children's school.

Being a parent to a child with health or mental health care needs can be difficult and exhausting. The parent is the child's primary caregiver and the key to his or her success. Therefore, it is very important that the parent learns as much as he/she can about the child's condition and needs, and develops partnerships with the child's doctors, therapists, and school staff. **A parent is a child's best advocate and must be informed to be successful.**

Background

The HSC Foundation supported the development of this pamphlet by partnering with George Washington University's Graduate School of Education and Human Development. A study was conducted by doctoral candidates Chandra Keller Allen and Jessica B. Forman, in collaboration with Maxine Freund, Ed.D. The study was developed to determine field knowledge and practices concerning service delivery to children with special health and mental health care needs. Three selected school districts in two Mid-Atlantic states participated in the study, which also looked at the extent and nature of interaction between education and health or mental health care professionals and challenges schools face in serving this group of children. Findings from the study informed the development of this pamphlet and are also intended to inform professionals as to how school systems serve children with special health care needs currently and where opportunities exist for innovation and service delivery improvement. The content of this pamphlet was reviewed and modified by groups of parents, youth, and educators outside the study area.

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Who are children with health or mental health care needs?

Children who have been diagnosed with health or mental health care needs are those who may:

- have chronic (continuing) medical, emotional conditions or behavior problems;
- miss a lot of school because of health or mental health-related problems or treatments;
- take prescription medicines; and/or
- need more health or mental health services than other children because of a chronic condition or conditions.

Children with health or mental health care needs include students with illnesses or conditions like but not limited to:

- juvenile diabetes
- asthma
- cancer
- diagnosed depression
- bipolar disorder
- attention deficit disorder (ADD or ADHD)
- spina bifida
- Down syndrome
- Epilepsy/seizure disorder
- sickle cell anemia
- cerebral palsy
- sensory integration disorders

Children with health or mental health care needs may also have a disability like mental retardation, emotional disorders, or autism.

What is one thing that is the same for all children with health or mental health care needs whether or not they have a disability?

- They need more health or mental health services than required by children generally.

Where can I get more information about my child's health condition?

- At public libraries
- Your child's school
- Doctors' offices and other health care providers
- Other community groups like churches or recreation centers
- Insurance companies
- Parent support groups
- Nonprofit organizations and advocacy groups
- Other parents you know

Tip

The Internet is a good source of information. If you don't have Internet access at home, computers with Internet access are available at public libraries.

What is the “medical home” concept?

- As a parent, you are the most important person in making the relationships with your child’s providers strong and lasting.
- A “medical home” is not a place. It is a *relationship* that you build to work together as a team with the health, mental health, educational, and other providers who take care of your child all of the time, on a regular basis.

Why is a medical home important for my child?

- A medical home gives better care to your child than when you just go to hospital emergency rooms and walk-in clinics, because the medical home staff actually know your child.

Why is it better to have care from the same providers all the time?

- You build a closer relationship with your child’s doctors over time.
- You feel more comfortable. Your child’s doctors will be able to provide better care because they know your child well.
- You won’t have to wait as long as you do in an emergency room or clinic. Most doctors’ offices have same day urgent care appointments.
- The other members of your child’s medical home, such as a school nurse, can talk to your child’s doctors and work together to improve care at school.

Who is a part of my child’s medical home?

- Your child’s health providers, like the pediatrician and other health specialists
- Your child’s mental health providers, like a therapist, psychologist, or psychiatrist
- Your child’s school staff members, like the school nurses, counselors, social workers, and teachers
- Your child’s vocational rehab counselor if he/she has one

Why should my child’s school be a part of a medical home?

- Your child is in school for a large part of his or her day.
- School staff members can take better care of your child along with you if they understand your child’s needs. They can also better teach your child if they know what health and mental health help your child needs.

How can I include my child’s school in the medical home?

- It’s important for you to share information about your child with school staff so they understand your perspective.
- Only *you* can give permission for different providers to talk to each other about your child.
- When you think it’s important, you can give permission for certain school staff members to talk directly with your child’s health or mental health providers.

When appropriate, include your child in the discussion when you work with the school. This is especially important as your child gets older and will help develop his or her self-confidence.

There are many state and federal programs that can help you with free or low-cost health care. Get in touch with Insure Kids Now at www.insurekidsnow.gov or call toll free at 1-877-KIDS-NOW.

Tips

Each state has at least one Parent Training and Information Center. Go to www.taalliance.org/centers/index.htm to get information on the parent center in your state.

How do I get to know my child's school family?

You are the expert when it comes to your child. However, there are people at your child's school who can be helpful, and you should feel comfortable talking to them.

Why should I talk to someone at my child's school?

- School staff members can do a better job of teaching your child if they know what health and/or mental health help is needed.

Who are some of the people I can talk to about my child's health or mental health care needs at the school?

- Classroom teacher
- School nurse
- School counselor
- School psychologist
- Principal or assistant principal
- School social worker
- Special education case manager
- Transition teacher or specialist

What should I expect from the school?

- To be treated as a key partner in your child's education and care.
- To get answers to your questions in a language you can understand, in writing if you ask for it.
- To be told about any health or behavior or emotional related problems that happen at school.
- To have a teacher, school nurse, counselor, or social worker answer questions about your child's needs.
- If your child has an Individualized Education Plan (IEP), it is your right by law to get a copy of parents' rights for special education to find out all of your rights under the law. The school or district must help explain all your rights to you if you ask.

Does everyone at the school have to know about our "personal business"?

It is up to you to decide what information you wish to share.

- When your child's doctor or therapist communicates with a school staff member, such as a teacher, counselor, or social worker, they have to keep the information **confidential** (private).
- When you share information with one staff member, be very clear about any other people you do and do not want the information shared with.

Questions to ask at the school:

- How often will I hear from the school about how my child is doing?
- How does the school team share information about my child?
- Do they meet regularly to review my child's progress and needs?
- Will the school nurse, school counselor, or school social worker be part of the information sharing and planning?

What if I don't agree with the school about my child?

- Let the school know as quickly as possible when you disagree with them.
- Try to work things out with school staff before calling someone at the district level. If you disagree with a teacher or staff member, ask the principal to help.
- If your child has an IEP, ask for a copy of your parents' rights. This explains what you can do next if you can't agree on what to do.
- Seek out your local parent information center or an advocate to help you.

Tip

You can get information on a school's standing or reputation through websites like www.PSK12.com and talking to other parents in the community.

What information should I give the school about my child's needs?

What should I bring to the school?

- Written reports about diagnoses, symptoms, behavior issues, dietary needs, allergies, treatment plans, assessments and evaluations, and medicine information. (If your child has been assessed, the school should already have some of this information.)
- Signed permission if you choose for an appropriate school staff coordinator of your choice to speak directly with your child's doctor and/or therapist.
- Information about how to reach you — and your child's doctors.
- A list of the things that may affect your child's learning. Tell the school if your child's condition or medicine causes him/her to be tired, have problems focusing, or have absences.
- Copies of **all** plans from your child's previous school(s) including Individualized Education Plans (IEPs), 504 plans, Individualized Health Plans (IHPs), or Behavior Intervention Plans (BIPs).

What if my child misses a lot of school because of health or mental health problems?

- Tell the school before any expected long-term absences.
- Ask the teacher or counselor how your child will get missed schoolwork. Ask how he/she will keep up with the class while he or she is out.
- Talk to your child's teachers or counselor about what will be explained to your child's classmates who ask about his or her absence.
- Talk to the teachers and other staff about working with them to help your child get used to being back in school after a long absence.

- Talk to your child and try to help him or her prepare for an absence from school and his or her return.
- Find out how to keep your child enrolled in the school (even with frequent and long absences) so that he/she can return to school when able.

Can a teacher come to our home when my child is going to be absent for a long time?

- Ask if your child is eligible for services at your home and how you can get them.
- Ask about getting a tutor for your child.

What if my child needs to take medicine during school hours?

- Ask the school nurse or other health staff about the school's medicine policy.
- Ask if you need to fill out a special form or have a letter from the doctor.
- Ask if the school health office staff will let you know when your child's medicine is about to run out.
- Ask how your child will know when to get his/her medicine.

Questions to ask at the school:

- What medical forms do you need from my child's doctor?
- Do you have a form for me to sign to give permission for you to talk to my child's doctor or therapist?
- Will school staff have contact with my child's doctor or therapist? Who will make the calls?
- Who is responsible for keeping the medical records on my child? Where are they kept?
- How are personal records on my child kept confidential (private)?
- Who is allowed to see my child's records?
- Who should I call with new information about my child?
- When will we meet to make a plan for my child? Who will come to the meeting?

What health or mental health services are available at my child's school?

School-based health and mental health services are different across the country. Ask questions at your school to find out what kinds of help and services are available for your child.

Is there a school nurse?

- Most schools have some kind of health office.
- It could be staffed by a full-time or part-time registered nurse or a health assistant or aide. Ask how often someone is in the health office.
- Ask what treatment and support the health staff is trained to give. Ask who is allowed to treat your child.

Are there health classes at the school? What kind?

- Most schools have a health education curriculum for all students. It is taught by the classroom teacher, a physical education teacher, or other health educator.
- The lessons are often about safety, self-care, eating healthy, drugs and alcohol, and making other healthy life choices.

Are there counselors in the school to help with emotional problems?

- Schools may have counselors, psychologists, or social workers.
- They may have small group or individual counseling sessions.
- If they don't provide counseling at the school, ask for a referral to counseling services in the community.

Do I have to pay for school counseling services?

- No. Any services given in the school should be **free**.
- School-based counseling services are different than therapy. Therapy is usually done with someone outside the school and can be paid for by health insurance. However, if therapy is in your child's IEP, it will be paid for by the school.

Does the school have programs to teach students not to pick on other students or bully them?

- School counselors, social workers, or health teachers may give class lessons on bullying or good social skills.
- Ask your child's teacher or the school counselor for more help if your child is being bullied or bullying others.

Is there a school-wide behavior management plan?

- Some schools use a school-wide positive behavior support program that gives different kinds of help to students.
- Ask the principal or school counselor about their school plan for supporting positive behavior.

Who can help me find additional resources in the community?

- Talk to your school nurse, social worker, school counselor, or school psychologist. Also you can contact your local parent information center or parent support group.

Questions to ask at the school:

- How will staff be trained about my child's health or mental health condition or disability? Can I help or be part of the training?
- Is there disability awareness training for students?
- How can I find out if my child needs physical therapy, occupational therapy, or speech/language therapy at school?
- What should I do if I think my child needs a personal nurse with her/him at school?
- If our neighborhood school can't meet my child's needs, where are the services going to be provided?
- How can I work with the school to make sure my child's IEP is followed and the needed services are provided?

How can I plan ahead for my child's transition to adulthood?

When your child is 14 years old and getting closer to becoming an adult, it's time to start thinking about planning for the time your child becomes an adult. This is called transition planning.

What should I be doing to prepare for my child becoming an adult?

- Talk to your child about his or her interests and dreams for the future.
- Help your child to develop independence. Help him or her learn the skills needed to get what he/she will need as an adult.
- Start planning for your child's health and/or mental health services as an adult.
- Begin to look for opportunities for work programs, volunteering, mentoring, and continuing education.
- Ask your child's school and other providers about youth development and independent living skills programs that will help your child move to adulthood.
- Make sure your child understands his or her strengths and weaknesses, and how that affects learning and interacting with others.

What kinds of things should we plan for?

- The requirements needed for graduating with a diploma or certificate of completion.
- If your child plans to attend post-secondary education, find out about:
 - College entrance requirements
 - The Free Application for Federal Student Aid (FAFSA)
- Where your child will live in the future
- Getting a job
- Switching from a pediatrician to a general adult doctor

What if my child has an IEP and is in special education?

- You and your child are entitled to take part in developing a childhood to adulthood transition plan as part of his or her IEP.
- When your child is between 14 and 16 years old, your IEP team should start talking about and writing a transition plan.
- Talk to your child's special education case manager or the transition teacher or specialist if you have questions about this process.
- Ask your child's guidance counselor to help you find an Office of Rehabilitation Services counselor. You can also directly contact your local Office of Rehabilitation Services to find out if your child is eligible to receive services.
- Ask if your child's school offers a Certificate of Completion, a high school diploma or GED – how are they different and what does that mean for your child?

Tips

Create a health management plan with your school and doctor to help your teenaged child learn to keep organized medical records. Your child will need to know where to get medical care, how to make follow-up appointments, and where to find information on diagnoses and treatment options that are available.

Many services in the community have wait lists. It is important to plan early to make sure your child has the help that's needed when he or she leaves school.

Understanding the School-Based Plans Your Child May Have

| Plan | What is it for? | School contact person: | Your role: |
|---|---|---|--|
| IFSP: Individualized Family Service Plan | Plan for early intervention services for infants and toddlers aged birth to 3 years. | Early intervention case manager. May be part of school district or may be a separate agency. | Make a request for evaluation, if needed. Take part in planning early intervention services and stay involved to make sure they're carried out. |
| IEP: Individualized Education Plan | Plan for education and related services for Pre-Kindergarten to 12 th grade students in special education. | Special education case manager | Ask for evaluation if you think your child has a disability. Take part in eligibility and annual IEP team meetings and ask for a copy. You should get IEP updates as often as your child gets a report card. |
| 504 Plan | Plan to address the unique needs of students with disabilities, but who do not qualify for special education. | It is different at different schools. Ask the principal or other school staff. | Ask for an evaluation, if needed. Take part in planning and ask for a copy of the plan. |
| IHP: Individualized Health Plan | Plan to address the special health care needs of students while in school. | Usually the school nurse | Give all health information that's important to your child's performance in school. Ask for a copy of the IHP. |
| FBA: Functional Behavioral Assessment | A process to address serious student problem behavior that sometimes comes before writing a Behavior Intervention Plan. | Usually the school psychologist | The IEP team will decide if an FBA is necessary before writing a BIP (see below). Parents may be asked to participate in the FBA process. |
| BIP: Behavior Intervention Plan | A plan to address special behavioral needs of students with emotional and/or behavior concerns at school. | Usually the school counselor, social worker, or psychologist; sometimes the special education teacher | Ask for a FBA plan so a BIP can be developed. Be part of the planning and stay involved. Ask for a copy and regular updates. |

Questions to ask at the school:

- How do I get my child evaluated for special education?
- Who should I talk to if I think my child needs a 504 plan?
- How will the school decide if my child needs an individualized health plan (IHP) or a behavior intervention plan (BIP)?
- Does the school district have a written policy about developing and using IHPs and BIPs? What is the policy and how do I get a copy of it?

Tip

Keep good records of all your child's evaluation reports and plans. Get regular reports on how things are going, especially for behavior plans. Be a part of all school meetings. Ask that they be held when you can be there.

Federal Laws that May Affect Your Child at School

| What is the law called? | Who is it for? | What does it provide? | How do I find out if my child is eligible? |
|---|---|---|---|
| No Child Left Behind (NCLB) | <ul style="list-style-type: none"> All school-age children | <ul style="list-style-type: none"> Focuses states and schools on proof of results, proven education methods, and choices for parents. Requires standard testing in reading, math, and science starting in the 3rd grade. | <ul style="list-style-type: none"> All school-age children are served under NCLB. |
| Individuals with Disabilities Education Improvement Act (IDEA) | <p>Children with an identified disability who are:</p> <ul style="list-style-type: none"> Infants and toddlers (birth up to 3 years old) Preschoolers (3-5 years old) School-age children (6-21 years old) | <ul style="list-style-type: none"> Home or center based early intervention therapies and services for infants and toddlers. Special education services for preschoolers and school-age children. An individual plan for your child's education and services. | <ul style="list-style-type: none"> Birth to 3 years – contact your state's IDEA Part C coordinator to find out how your child can be assessed for early intervention services (see Resources). School-age children - ask your child's school psychologist, principal, or special education teacher how the process works at your school. Ask (in writing) that your child be tested for eligibility. |
| Section 504 of the Rehabilitation Act | <ul style="list-style-type: none"> School-age students who have a disability that limits a major life activity but may not affect their schoolwork | <ul style="list-style-type: none"> Protection from discrimination by the school based on a student's disability. An individual plan that outlines the adjustments and changes your child will receive in school. | <ul style="list-style-type: none"> Ask your child's principal, school psychologist, or school counselor how the 504 process works at your school. Ask (in writing) that your child be considered for eligibility for a 504 plan. |
| Section 508 of the Rehabilitation Act | <ul style="list-style-type: none"> All children and adults with disabilities | <ul style="list-style-type: none"> Guidelines to Federal agencies so electronic information they provide can be accessed and used by individuals with disabilities. | <ul style="list-style-type: none"> If your child has an identified disability, he or she is covered under Section 508. |
| Title V of the Social Security Act | <ul style="list-style-type: none"> Children with special health or mental health care needs | <ul style="list-style-type: none"> Each state decides what types of programs and services to offer to help all children have a medical home; services might include care coordination and help with getting health insurance. | <ul style="list-style-type: none"> Contact the person in your state responsible for the Title V program. To find out more, visit : http://cshcnleaders.ichp.edu |
| The Americans with Disabilities Act (ADA) | <ul style="list-style-type: none"> All children and adults with disabilities | <ul style="list-style-type: none"> Protection from discrimination because of a disability in the work place, public schools, other public facilities, commercial facilities and transportation. | <ul style="list-style-type: none"> If your child has an identified disability, he or she is protected from discrimination with this law. |

ADDITIONAL RESOURCES

Medical Home and Health Care Resources

Medical Home Improvement
www.medicalhomeimprovement.org

National Center of Medical Home Initiatives for Children with Special Needs
www.medicalhomeinfo.org

Insure Kids Now
www.insurekidsnow.gov or toll free at 1-877-KIDS-NOW

Center for Health and Health Care in Schools
www.healthinschools.org

Health Care Coach
www.healthcarecoach.com

Covering Kids & Families
coveringkidsandfamilies.org

American Academy of Pediatrics
www.aap.org

Mental Health Resources

Mental Health Services Locator
www.mentalhealth.samhsa.gov/databases

Center for School Mental Health Analysis and Action
www.csmha.umaryland.edu

Center for Mental Health in Schools
www.smhp.psych.ucla.edu

National Alliance on Mental Illness
www.nami.org

National Association of School Psychologists
www.naspcenter.org

Child and Adolescent Mental Health
www.mentalhealth.samhsa.gov/child/childhealth.asp

Family Support and Parent Involvement Resources

Family Voices
www.familyvoices.org

Family Village
www.familyvillage.wisc.edu/websites.html

Parent Advocacy Coalition for Educational Rights
www.pacer.org

Parent Training and Information Centers
www.taalliance.org/centers/index.htm

National Parent Teacher Association (PTA)
www.pta.org/homepage.html

National Coalition for Parent Involvement in Education
www.ncpie.org

Disability or Special Education Resources

State IDEA Part C Coordinators
www.nectac.org/contact/ptccoord.asp

State IDEA Part B Coordinators
www.nectac.org/contact/619coord.asp

The National Early Childhood Technical Assistance Center
www.nectac.org

National Association of State Directors of Special Education
www.nasdse.org

The Council for Exceptional Children
www.cec.sped.org

Your Rights under Section 504
www.hhs.gov/ocr/504.html

National Dissemination Center for Children with Disabilities
www.nichcy.org

Special Education Resources on the Internet
www.seriweb.com

Child Find Resource
www.childfindidea.org

Parent Training and Information Centers and Community Parent Resource Centers for Children with Disabilities
www.taalliance.org/centers/index.htm

Schwab Learning
www.schwablearning.org

Americans with Disabilities Act
www.ada.gov

Wrightslaw – Understanding Special Education Law
www.wrightslaw.com

CECP – Functional Behavioral Assessments
<http://cecp.air.org/fba>

Transition Resources

Vocational Rehabilitation State Offices
<http://www.jan.wvu.edu/SBSES/VOCREHAB.htm>

Adolescent Health Transition Project
www.depts.washington.edu/healthtr/index.html

National Youth Employment Commission
www.nyec.org

Youth Rules!
www.youthrules.dol.gov

JOB CORPS
www.jobcorps.dol.gov

Student Resources
www.nacacnet.org

Register for the SAT
www.collegeboard.com/splash

The ACT: Information for Parents
www.act.org/path/parent

Free Application for Federal Student Aid
www.fafsa.ed.gov/

Colleges
www.colleges.com

National Collaborative on Workforce and Disability for Youth
www.ncwd-youth.info

Career One Stop
www.careeronestop.org or toll free at 1-877-US-2JOBS

Youth Development and Leadership
www.dol.gov/odep/categories/youth/youth.htm

MISSION

The mission of The HSC Foundation is to facilitate access to appropriate services for individuals with special needs and their families in the Washington metropolitan area, and to participate in related local, regional, and national projects with government, private, and philanthropic organizations.



THE HSC HEALTH CARE SYSTEM

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