

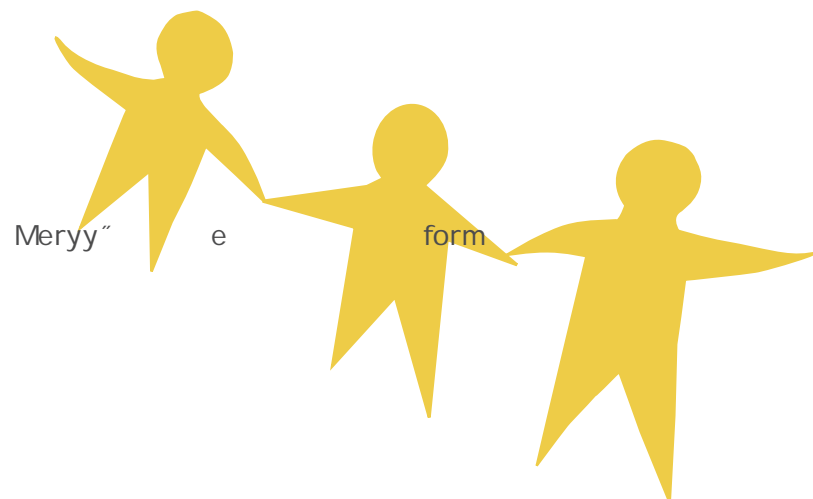
## Introduction

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.



## 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.

*K \ Uh]g'cbY'h ]b[ 'h Uh]g'h Y'gUa Y'Zcf'U''VX]XfYb' k ]h' \ YU'h 'cf'a YbHJ'' \ YU'h 'WfY'bYYXg:k \ Yh Yf' cf'bch'h Ym\ Uj Y'U'X]gUV']mB*

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

*K \ YfY' WUb' = [ Yh' a cfY' ]bZcfa Uh]cb' UVci h' a m' Vx]XfY' \ YU'h 'Vt'bx]h]cb3*

- 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

*H\ Y' =bhYfbYh]g'U'[ ccX' gci fVW'cZ]bZcfa Uh]cb'' =Zmci 'XcbB'i\ Uj Y' =bhYfbYh'UWVYgg'Uh'\ ca YZ' Vt'a di hYfg'k ]h' =bhYfbYh' UWVYgg'UfY'Uj U]UV'Y'Uh'*

## 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 *fY`Uh]cbg\]d* 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.

### *K \m]g`U`a YX]W` \ca Y`ja dcfhUbh`Zcf`a mVX]X3*

- 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.

### *K \m ]g` ]h` VY`hYf` hc` \Uj` Y` WUfY` Z`ca` h\Y` gUa Y` dfcj ]XYfg`U` h\Y`h]a Y3`*

- 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.

### *K \c` ]g`U`dUfh`cZ`a mVX]X`a YX]W` \ca Y3`*

- 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

### *K \m ]g`ci` X` a m VX]X`g`gV`cc` VY` U` dUfh` cZ` U` medical` \ca Y3`*

- 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.

### *<ck` WUb` =]bV` XY`a mVX]X`g`gV`cc` ]b` h\Y`a YX]W` \ca Y3`*

- It's important for you to share information about your child with school staff so they understand your perspective.
- Only *mci* 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.

### *K \Yb` Uddfcdf]UHYZ` ]bV` XY` mci` f` VX]X` ]b` h\Y` X]gV`gg]cb`k` \Yb`mci` `k`cf`\_`k` ]h` h\Y`gV`cc` "H\ ]g` ]g` YgdYV]U`m]a` dcfhUbh`Ug`mci` f` VX]X` [Yhg`c`XYf`UbX` k` ]` \Y`d`XYj`Y`cd` \]g`cf` \Yf`gY`Z` V`b`U`X`Y`b`W`"*

*H\YfY`UfY`a` Ubm]ghUHY`UbX`  
ZYXYfU`dfc[ fUa`g`h`Uh`WUb`  
\Y`d`mci` `k` ]h` Z`FY`cf` `ck`!  
V`gh` \YU`h` WUfY"; Yh` ]b` hc`i` V`  
k` ]h` =bgi` fY`? ]Xg`Bck` Uh`k`k`k` "  
]bgi` fY`\_ ]Xgbck` "[cj`cf`W` `hc` "  
Z`FY`Uh`%d, ++! ? =8G!BCK` "*



*9UVX`ghUHY` \Ug`Uh`YUgh`cbY`  
DUfYbh`HfU]b]b[ `UbX` =bZ`fa` Uh]cb`  
7YbhYf"; c`hc`k`k`k` "hUU` ]UbW` "  
cf[ #W`bhYfg#]bXYI` "\ha`hc` [Yh`  
]bZ`fa` Uh]cb`cb`h\Y`dUfYbh`  
W`bhYf` ]b`mci` f`ghUHY`"*

- 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.

*E i Ygh]cbg'hc'Ug\_ 'Uh'h\Y'gW\cc`.*

- 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?

*K \Uh' ]Z = 'Xcb\U[ fYY'k ]h' h\Y'gW\cc` UVci h'a m W\]X3*

- 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 teachb

ib el. b shú MafiÉ

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

*K \ Uh'g\ci 'X'='Vf]b[ 'hc'h\Y'gWcc'3'*

-

## 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.

*g'h YfY' U' gWcc' bi fgY3*

- 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.

*5fY' h YfY' \ YU' h' WUggYg' Uh' h' Y' gWcc' :3' K \ Uh' ]bX3*

- 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.

*5fY' h YfY' Vti bgY' c' fg' ]b' h' Y' gWcc' : h' \ Y' d' k ]h' Ya ch]cbU' d' fcV' Ya g3*

- 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.

*8c' = \ Uj Y' h' d' UmZ' c' f' gWcc' Vti bgY' ]b[ ' gYfj ]Wg3*

- 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.

*8cYg'h Y' gWcc' \ Uj Y' d' fc[ fUa g' h' c' h' YUW' ghi XYbhg' bch' h' c' d' ]W' cb' ch' Yf' ghi XYbhg' c' f' Vi' `mi' h' Ya 3*

- 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.

*=g' h' YfY' U' gWcc' :!k ]XY' VY\ Uj ]c' f' a UbU[ Ya Ybh' d' Ub3*

- 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.

*K \ c' WUb' \ Y' d' a Y' UbX' UXX]h]cbU' fYgci fWg' ]b' h' Y' Vta a i b]m3*

- 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.

*E i Ygh]cbg' h' Ug\_ 'Uh' h' Y' gWcc' :*

- 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?





Plan	What is it for?
<b>IFSP: Individualized Family Service Plan</b>	Plan for early intervention services for infants and toddlers aged birth to 3 years.
<b>IEP: Individualized Education Plan</b>	Plan for education and related services for Pre-Kindergarten to 12 <sup>th</sup> grade students in special education.
<b>504 Plan</b>	Plan to address the unique needs of students with disabilities, but who do not qualify for special education.
<b>IHP: Individualized Health Plan</b>	Plan to address the special health care needs of students while in school.
<b>FBA: Functional Behavioral Assessment</b>	A process to address serious student problem behavior that sometimes comes before writing a Behavior Intervention Plan.
<b>BIP: Behavior Intervention Plan</b>	A plan to address special behavioral needs of students with emotional and/or behavior concerns at school.

E i Ygh]cbg'hc`Ug\_`Uh'h\Y`gVXcc`:

•

What is the law called?

Who is it for?

No Child Left Behind (NCLB)

## ADDITIONAL RESOURCES

### **Medical Home and Health Care Resources**

Medical Home Improvement

[www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org)

National Center of Medical Home Initiatives for  
Children with Special Needs

## Disability or Special Education Resources

State IDEA Part C Coordinators  
[www.nectac.org/contact/ptccoord.asp](http://www.nectac.org/contact/ptccoord.asp)

State IDEA Part B Coordinators  
[www.nectac.org/contact/619coord.asp](http://www.nectac.org/contact/619coord.asp)

The National Early Childhood Technical Assistance Center  
[www.nectac.org](http://www.nectac.org)

National Association of State Directors of Special Education  
[www.nasdse.org](http://www.nasdse.org)

The Council for Exceptional Children  
[www.cec.sped.org](http://www.cec.sped.org)

Your Rights under Section 504  
[www.hhs.gov/ocr/504.html](http://www.hhs.gov/ocr/504.html)

National Dissemination Center for Children with Disabilities  
[www.nichcy.org](http://www.nichcy.org)

Special Education Resources on the Internet  
[www.seriweb.com](http://www.seriweb.com)

Child Find Resource  
[www.childfindidea.org](http://www.childfindidea.org)

Parent Training and Information Centers and Community Parent Resource Centers for Children with Disabilities  
[www.taalliance.org/centers/index.htm](http://www.taalliance.org/centers/index.htm)

Schwab Learning  
[www.schwablearning.org](http://www.schwablearning.org)

Americans with Disabilities Act  
[www.ada.gov](http://www.ada.gov)

Wrightslaw – Understanding Special Education Law  
[www.wrightslaw.com](http://www.wrightslaw.com)

CECP – Functional Behavioral Assessments  
<http://cecp.air.org/fba> **Wrig** **Law** **M**

## 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.

