

Stepping Stones



Parent Education & Advocacy Leadership Center

*Promoting inclusion and access
in education and healthcare*

*Empowering families and
young adults across PA*

Care Maps

Care for children and youth with special health care needs (CYSHCN) can be challenging to coordinate given the complexity of systems and involvement of multiple services and providers. Families are often responsible for:

- making appointments
- getting children to therapies and appointments
- filling prescriptions
- resolving insurance problems and finding ways to pay for uncovered expenses
- serving as the backup home health nurse

These responsibilities may take hours to coordinate and can be exhausting, especially in addition to running a home and maintaining employment.

A care map is a family-centered visual tool that illustrates the network of care for CYSHCN, including medical, educational and other support systems. (See example on side 2.) It is powerful to visualize the services, linkages, and interconnections for children and young people who have complex medical issues. It provides an overview and the details that can be used to understand the value of:

- working together to most effectively meet needs,
- tackle barriers, and
- drive ongoing services.

Cristin Lind first created a care map when she was asked to explain what was involved in raising her child with special needs. Families create the care map and use it to guide discussions with providers to talk about the impact on the child and the family. A care map should be created in a way that is meaningful to the family. Families that have more than one child with special health care needs can create one overlapping care map.

! *Tip: Create your care map in a way that is meaningful to you and easy to update as changes occur.*



A care map can be used to start a conversation with providers, teachers and community agencies to educate them about the added time and stressors involved in raising a child with special health care needs. Families may need to decrease or stop working which can create financial challenges, increase strain in relationships and/or cause basic needs to go unmet.

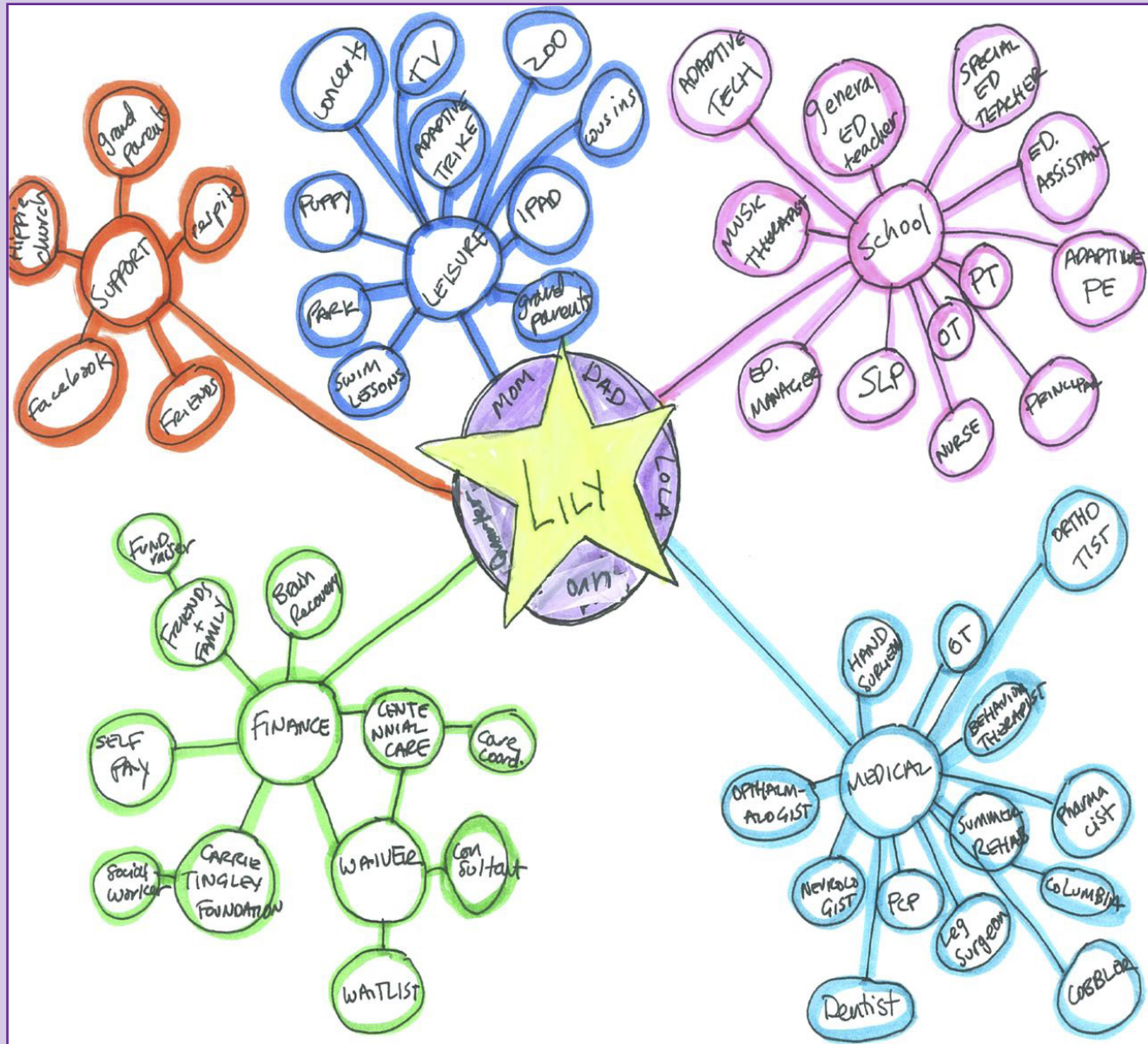
Care Maps can be used as a tool to:

- Arrange and maintain services
- Prioritize
- Identify and avoid duplications and gaps
- Coordinate care and create a Care Plan
- Identify potential referrals
- Prepare for the future and transitions
- Advocate and educate others

A care map is a tool that has the power to have a positive impact in shaping outcomes for the individual and their family.

Kidspiration (see Resources on Side 2) and other concept mapping apps or templates can be used to create care maps with technology.

Care Map



Used with permission from Cristin Lind, <http://www.cristinlind.com>.

Resources

1. **Kidspiration:** <https://bit.ly/33gytCy>
2. University of Toronto: **Care Plans and Care Maps: Innovative Tools to Improve the Care of Children with Special Health Care Needs** <https://bit.ly/3hxwq1b>
3. Boston Children's Hospital: **Organizing Care and Relationships for Families: Care Map** <https://on.bchil.org/2OLEb70>
4. Children's Wisconsin: **A Picture Paints a Thousand Words: Care Maps Help Families Identify What Matters Most** <https://bit.ly/2WLN1WK>
5. Lucile Packard Foundation for Children's Health: **Family Stories** (photos, information, and care maps from real families) <https://bit.ly/2BleUNZ>
6. American Academy of Pediatrics: **Care Coordination for Children With Medical Complexity: Whose Care Is It, Anyway?** <https://bit.ly/3ePrOle>

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Nursing & Medication Administration

School Nurses



Certified school nurses address a wide range of needs. The school nurse is responsible for maintaining medical records, reporting contagious diseases, and providing health screening and training. Every district is required to have 1 nurse for every 1,500 students. However, their responsibilities vary among districts. Nurses may travel between buildings, and substitute nurses may not be available. If your child receives ongoing nursing services from the school nurse, frequent communication is essential.

The school nurse is responsible for the health care needs of children with special health care needs, providing specialty care, administering medications, and implementing individual health care plans. The school nurse may need to address specific situations, such as an asthma attack or seizure; to complete scheduled procedures or administer medications.

School nurses participate on 504, IEP, and Student Assistance Program (SAP) teams. They also coordinate with the providers of medically necessary “outside” nursing services.

If a child needs to have medication during the school day, families should be familiar with district medication administration policy. Ask the nurse or principal about any questions related to your child’s needs. If they indicate that regulations or policies prohibit your child from receiving medications, ask that they share the documentation.

Considerations for families to consider regarding school nurses:

1. How long is the nurse’s response time to reach your child?
2. Is a nurse in the building during extra-curricular activities?
3. What is the emergency procedure and response time during transportation to and from school?
4. How does your child get needed support during lock-downs and drills?
5. What is the back-up plan?

!
If you are the parent or caretaker of a child with disabilities or special health care needs, the PEAL Center has other Stepping Stones issues that may be helpful to you on such topics as Individual Health Care Plans, Health Issues and Instructional Options, Truancy and Attendance, and more.

Agency Nursing Services at School

Some students require individualized services of an Registered Nurse, Licensed Practical Nurse, or nurse's aide at school. These nursing services, provided by a home health care agency, must be approved by medical insurance.

The responsibilities of agency nursing providers vary and are based on physician's orders and in accordance with the agency's plan of care.

Depending upon the physician's orders, agency nursing staff may provide:

- door-to-door care (i.e., travel to and from school with the student)
- part- or full-time care during the school day
- support at extra-curricular and/or field trips.

Agency nursing staff work in cooperation with the school staff, primarily the certified school nurse and student's teacher(s).

Schools can host a meeting with the family, agency nursing staff and school staff to address conflicts and resolve issues. Open lines of communication and focus on meeting the student's needs should be priorities.

The availability and skill set of substitutes can be a concern and should be part of a plan.

If schools will not accept an outside provider, contract with a specific agency, or no provider is available, they have the obligation to provide nursing for a student for whom it is medically necessary. These needs should be addressed in the 504 or IEP, whether an outside provider is used or not.



Resources

IDEIA and Section 504 Teams - The School Nurse as an Essential Team Member (Position Statement).

National Association of School Nurses

<https://bit.ly/3e5NKrD>

The Role of the School Nurse in the Special Education Process. School Nursing 101

<https://bit.ly/2ZA1oya>

School Health and Nursing Services for Students with Disabilities in the Public School Setting.

McAndrews Law (Pennsylvania)

<https://bit.ly/3gwOWpV>

Model Policy for the Management of Students Requiring a Private Duty Nurse in Schools.

Maryland State Department of Education

<https://bit.ly/2YYFUMn>

1:1 Nursing Services for Students with Special Health Care Needs. Wisconsin Department of Public Instruction

<https://bit.ly/38vRfqj>

The Medically Fragile Child. Caring for Children with Special Healthcare Needs in the School Setting. American Federation of Teachers (AFT)

<https://bit.ly/30antVC>



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A Mom's Story

Ashley Manthey of Dauphin County has two sons with hydrocephalus, a chronic condition in which fluid creates pressure on the brain. Both boys have shunts to relieve the pressure.

If a shunt fails, however, brain damage or even death could result. **For Ashley and her family, it is critical that school personnel recognize the symptoms of shunt failure and know what action to take.**

Without Individual Health Care Plans in place for her boys, Ashley notes that she "would not have the peace of mind to let them walk into school each day, away from my watchful eye."

Read more of Ashley's story in *Why your child needs an IHP* in the Central Penn Parent @ <https://bit.ly/3dkSjy0>.

If a student needs an Action Plan to address emergencies related to Asthma, Seizure, Anaphylaxis and/or Diabetes, these plans are usually written by the physician and shared with the school.

What is an Individual Healthcare Plan?

An Individual Healthcare Plan (IHP, IHCP or HCP) is **a tool developed by a school nurse in cooperation with the student/family to address the needs and goals of a student with medical complexity.** This plan identifies the student's condition(s)/problems and helps school staff be aware of the health care needs of the student while in school, specifying what must be done and by whom. IHPs provide a proactive framework for school staff to understand a student's medical issues, how those issues impact their school experience, and how to deal with related emergency situations.



An Individual Healthcare Plan for school should include:

- A list of individuals who need to understand the plan to ensure the student's safety
- A description that is understandable to non-medical staff:
 - signs, symptoms, and triggers to be aware of
 - a plan of action for when the condition impacts the child
- Training that is needed for staff and/or students
- Information specific to extracurricular activities, transportation, and field trips, if needed
- An Emergency Plan if the student has a life-threatening condition
- Criteria for calling 911 or other first responders
- Criteria and process for contacting the family

An IHP may also address:

- Avoidance of allergens and triggers
- Reasonable accommodations
- Procedures for student to carry medications and self-medicate
- Attendance and/or transportation concerns
- Administration of emergency medications

Healthcare plans are generally kept in the nurse's office and can be embedded in or attached to an IEP or 504 plan.

It is a good idea to discuss the IHP with your child's doctor to be sure that it is accurate and consistent with best practices. An Alternative Attendance Plan may be included in the IEP/504 if a health condition is expected to result in excessive absences. This type of plan may require a letter from a doctor.

Regular communication with the school nurse who is responsible to coordinate the health care needs of students while in the school is important, not only to develop a trusting relationship, but also to address changing needs and update plans. It is important to **share information from healthcare providers, respond to the nurse's requests for supplies, medications, prescriptions, or information** in the cooperative effort to see that your child's healthcare needs are met.

Creating an IHP

Family should:

- Discuss health issues and how they affect your child at school with healthcare provider(s).
- Ask provider(s) to document health issues, needs and specific recommendations.
- Share and discuss documentation from health care provider(s) with the school nurse.

School Nurse should:

- Use assessment tools to gather more information about your child; consult with healthcare provider(s); review medical records; and talk with the student and school personnel.
- Develop a nursing diagnosis that outlines nursing interventions and measurable outcomes for the school setting.
- Establish measurable goals to monitor progress of problem resolution, improved health status, and/or continued maintenance of good health.

IHP EXAMPLE*

Nursing Diagnosis	Goals	Nursing Interventions	Expected Outcomes
Alteration in communication due to tracheostomy	Student has increased independent communication skills	>In-service training to promote effective communication >Staff should stand in front of student, use eye contact and good volume.	Student will increase communication by one verbal or nonverbal cue weekly.



*Cynthia K. Silkworth, Jartha J. Arnold, Judith F. Harrigan, Donna Shipley Zaiger, eds., Individualized Healthcare Plans for the School Nurse, Concepts, Framework, Issues, and Applications for School Nursing Practice. (PDF version of document downloaded 21 June 2020 from <https://www.schoolhealth.com>).



Resources

- **Individualized Healthcare Plans for the School Nurse**
Concepts, Framework, Issues, and Applications for School Nursing Practice <https://bit.ly/2CwmXbf>
This abstracted publication, written for school nurses but also informative for families, provides a thorough description of the IHP process and students with chronic health conditions.
- **Top Ten Tips for Individual Healthcare Plan (IHP)**
PTI Nebraska <https://bit.ly/3hON11i>
Tips to help families to get started on the IHP process.
- **Individual Healthcare Plan Process**
Colorado Department of Education <https://bit.ly/3fHYVYW>
A more detailed discussion of the IHP process.
- **Individual Student Healthcare Plan Templates**
San Diego County Office of Education <https://bit.ly/2WHnoq7>
Downloadable Word documents for over 90 medical conditions that can be customized. Includes plans for students with Autism, Anaphylaxis, Cerebral Palsy, & Hemophilia, Traumatic Brain Injury, & more.
- **Plans of Care for Students with Special Health Care Needs**
Pennsylvania Department of Health <https://bit.ly/319Zl6a>
A brief discussion of specific plans to support students, such as Individualized Healthcare Plans (IHP), Emergency Care Plans (ECP), Individualized Education Program with medical component (IEP), Individualized Transportation Plan (ITP), and 504 Service Agreement.

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When Health Issues Prevent Attending School

Some students experience health-related issues that make school attendance difficult or impossible. Mental health issues can also affect attendance. When a student who has an IEP is experiencing health issues that may temporarily prohibit school attendance, the IEP team should revise the IEP as necessary. If there is a change in the student's need for specially designed instruction, the school may need to reevaluate the student. **There are two distinct ways that a school can provide instruction** to a student with an IEP who cannot attend school for a period of time due to health-related issues.

1. Homebound Instruction— Available to all Students

A student who, due to a mental, physical or other urgent reason cannot attend school may be eligible for **Homebound Instruction**. Homebound instruction temporarily excuses a student from compulsory attendance rules for up to three months. School districts must have a homebound instruction policy. Homebound instruction will ideally keep the student on pace with their classes. Teams need to consider what the student is able to complete, when, for how long, and what instruction is needed. Districts that offer cyber and online programs may offer these as an option for students on homebound instruction.

It is important to recognize that some students may not be able to participate in instruction during this temporary excusal due to their health condition.

For students who have an IEP, the team should meet to consider how a student's needs can best be met during homebound instruction. The instruction the student is receiving should be designed to enable the student to receive meaningful educational benefit through the services, supports, and hours of homebound instruction. **For those who do not have an IEP**, the family can request a 504 plan.



2. Instruction Conducted in the Home—a Special Education Placement

The IEP team must determine if a student needs to be educated at home. How the student will receive Specially Designed Instruction (SDI) needed to provide FAPE.

One option for the IEP team is to change the child's placement to **Instruction Conducted in the Home**. This educational placement is considered to be the "most restrictive" because the student does not have any interaction with non-disabled peers. Special education services and supports are individualized. For example, a student may have several hours of instruction following a schedule that meets the student's needs. They may be served by subject area teachers, special educators, and receive related services at home or via telehealth.

Technological options such as web conferencing, distance learning, video conferencing, and virtual classrooms can connect students to instruction and, when appropriate, provide access to teachers, peers, and additional participation and learning opportunities.

continued on next page

Families need to be aware of the options for a student with a disability who cannot attend school in person. Whether a student receives Homebound Instruction or Instruction Conducted in the Home while they are unable to attend school, it is important to have a plan for when and how they will transition back to school. This is particularly important when the student is unable to attend school due to mental health issues or trauma.

Doctors may not be aware of special education and 504 options of the limited services provided through "homebound instruction." A doctor who is prescribing homebound instruction may not be aware that a student who receives Special Education services, may be entitled to receive FAPE via Instruction Conducted in the Home.

If your special education student is recommended for homebound, the IEP team should meet to consider whether ICITH is appropriate to meet their needs during the time when their physical or behavioral health precludes them attending school.



Resources

Pennsylvania Department of Education:

→ **Homebound Instruction:**

<https://bit.ly/2VGuMBE>

→ **Instruction Conducted in the Home:**

<https://bit.ly/2D1ceWd>

→ **Reporting Special Education Students who receive Homebound or Instruction Conducted in the Home:**

<https://bit.ly/2BZgLU>

	Homebound Instruction	Instruction Conducted in the Home
Who is eligible to receive this service?	All students—both general education students and students who receive special education services	Students who have an IEP or who are determined to be eligible to receive special education services.
How and when are the need for services determined?	<ul style="list-style-type: none"> → Parent initiates request and provides a doctor's note indicating a medical or psychological issue → School makes the decision for the student to receive Homebound Instruction → Student is excused from compulsory attendance due to temporary mental or physical illness or other urgent reasons 	<ul style="list-style-type: none"> → IEP team meets and makes a decision that this placement is necessary to provide FAPE, keeping in mind that this is the most restrictive educational placement. → Notice of Recommended Educational Placement (NOREP)/Prior Written Notice (PWN) is issued and signed by parent/guardian.
Who provides instruction?	A Certified Teacher—Special education services, must be delivered by a certified Special Education teacher.	Instruction must be provided by a certified Special Education teacher consistent with the student's IEP.
Where is instruction provided?	Instruction is delivered in the student's location (e.g., home, hospital, treatment facility).	Instruction is delivered in the student's home or a mutually agreed upon location that is decided by the IEP team (such as a local library).
How long can a student receive this service?	<ul style="list-style-type: none"> → May not exceed 3 months unless the school receives approval from the Pennsylvania Department of Education to extend the provision of Homebound Instruction → Depends on school policy and the student's condition 	<ul style="list-style-type: none"> → For the length of the IEP (the IEP can be reviewed and changed at any time but must be updated at least annually). → Determined by the IEP team, based upon the student's condition

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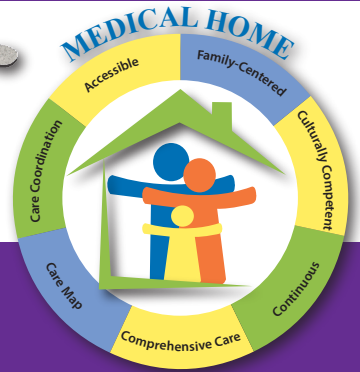
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WHAT IS A MEDICAL HOME?

There are different styles of primary care practices. A Medical Home Model of primary care may be the type of pediatric primary care that your child needs.

Medical Home is an approach, not a place. It is a way of delivering health care through the primary pediatrician's office, where the patient gets their regular care.



A Medical Home is driven by family goal-setting and participation.



A practice can be recognized as a "Medical Home" in various ways. There is not one standard definition of a Medical Home. It is important to learn what this means to your provider, child and family.



WHAT MAKES A MEDICAL HOME?

This model is beneficial for children and youth who have complex health care needs. The provider partners with the patient and family to coordinate the patient's care with all of the others involved—such as specialists, schools, and community organizations. The goal is to deliver the best possible care to the patient in a coordinated fashion. **Key features of a Medical Home practice are:**

1. ACCESSIBLE: It is easy for the patient and family to get appointments, referrals, and services. The medical team spends enough time with each patient to understand and address all needs.

2. FAMILY-CENTERED: Medical decisions are made WITH the family—respecting their wants, needs, and preferences. A Medical Home recognizes that parents/caregivers are the expert in their child's care.

3. CULTURALLY COMPETENT: The providers have a sensitivity to differences in culture, language, beliefs, and traditions of the family. These differences are recognized, valued, and respected.

4. CONTINUOUS: The same medical team cares for the patient until they transition to adult care. The provider and patient/family learn about and respect each other. Continuity of medical team members is ideal for monitoring patient care. Medical Home providers facilitate smooth transitions from hospital to home and/or outpatient and from infant care through transition to adulthood.

5. COMPREHENSIVE CARE: All providers work as a team to meet the patient's needs, including prevention, wellness, acute, and chronic care. Staff make referrals and connections to additional resources.

6. CARE PLAN: A tool to help understand the "big picture" of the patient's supports. It is created in partnership with the family and shows the entities involved in the patient's care and support. The care plan describes the roles of each clinician, agency and organization in providing coordinated services and supports to deliver medical care in ways that are based upon the Medical Home concepts.

7. CARE COORDINATION: A Care Coordinator may facilitate meetings of the Care Team (those who care for the patient's comprehensive needs), help with the development, revisions, and implementation of a Care Plan, and to manage transitions. They may assist with scheduling appointments, ordering supplies, or connecting the family with other providers, agencies and organizations.



WHY SHOULD YOU WANT OR SEEK A MEDICAL HOME?

Beyond just asking if the practice follows a Medical Home model, consider asking additional questions:

- What does Medical Home look like in your practice?
- What is different because you follow this model?
- Do you have an individual who supports families in Care Coordination?
- Will we see the same provider at each visit?
- What are your office hours? How can I access the practice after hours?
- Do you have parent partners or advisers?
- Does anyone in the practice support transition from inpatient to outpatient and into adult oriented systems?

Perhaps you cannot locate a Medical Home practice or your child/youth is already seeing a doctor who does not follow the Medical Home model.

What steps can you take to begin to build medical home idea into your child's practice?

1. Visit the PA Academy of Pediatric Medical Home website to learn more about the hallmarks of Medical Home.
2. Share material, websites, or stories about the benefits of Medical Home concepts.
3. Talk to the medical team about elements of Medical Home that would be beneficial.
4. If your child's practice applies the concepts of the Medical Home but does not have certification, encourage them to become a recognized medical home practice.



Pennsylvania Medical Home Initiative

For more information or to schedule a presentation:

- See www.pamedicalhome.org
- Email: pamedicalhome@paaap.org
- Follow: www.facebook.com/pamedicalhome
- Contact:
Dr. Renee Turchi, PA Medical Home Initiative Medical Director
Eileen Thompson, Program Director
484-446-3011,
ethompson@paaap.org

Check out this recent article in Pediatrics, *Incorporating Patient- and Family-Centered Care Into Practice: The PA Medical Home Initiative*, co-authored by Dr. Renee Turchi @ <https://bit.ly/2w7810l>.

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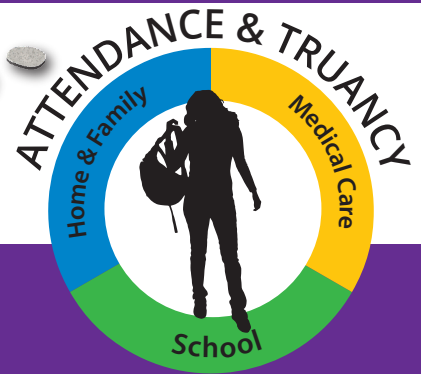
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Truancy & Students With Chronic Health Conditions

Students with chronic conditions often have excessive absences due to their health, surgeries, appointments, etc.



While there is no limit to medically excused absences, **unexcused absences** are limited.



Pennsylvania truancy law defines **truancy** as **three unexcused absences**, and **habitual truancy** as **six unexcused absences**.

Truancy: Understanding Your Rights

Families who have children with chronic conditions need to be familiar with School District attendance policies. Districts usually require a medical excuse after a certain number of absences. If a family does not provide a medical excuse after the specified number of absences, this results in an “unexcused” absence.

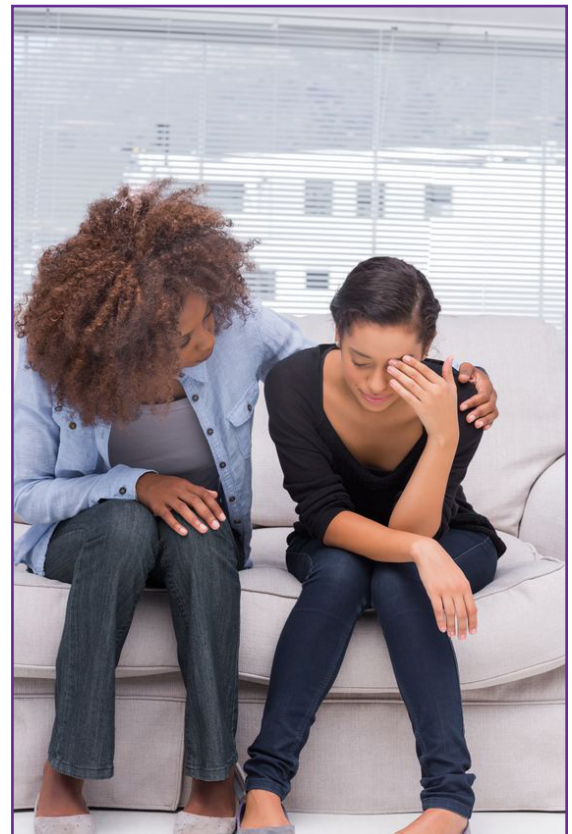
Written excuses are sometimes lost or not received by the school. Suggested steps for families:

- **Devise a system to record your child’s absences**
- **Keep a copy of all excuses**
- **Ask your child if they turned in their excuse**

If you receive a truancy letter, ask for a copy of the student’s attendance record for the year and compare it to your records. While there are district policies about the time limit for submitting excuses, if one is missing, send it in and ask that it be accepted.

PA Act 138 went into effect beginning in the 2017-2018 school year to **prevent inappropriate or harsh truancy responses by schools**. The legislation was passed to improve school attendance and reduce truancy “to consistently identify and address attendance issues **as early as possible** . . .” and use evidence-based practices to:

- ☑ Preserve the unity of the family whenever possible by addressing underlying issues of truancy.
- ☑ Avoid entry of children into foster care, the loss of housing, and other unintended consequences that disrupt an intact family unit.
- ☑ Eliminate or reduce the amount of time a parent or guardian is detained for truancy-related offenses. Detaining a parent/guardian should only be used as a last resort.



Student Attendance Improvement Conference (SAIC)

Before sending a family to a magistrate for truancy issues, the school is required to hold a Student Attendance Improvement Conference (SAIC) to discuss the reasons for the child's absences and develop a written plan to improve attendance. The plan may include connecting the student and/or the family with additional services. When a student has a 504 plan or IEP, the SAIC should consider if the absences are related to the student's health/condition. Schools should make every attempt to have the person in parental relationship present at the SAIC, including rescheduling to accommodate the parent's schedule. ***It is important to attend an SAIC for your child and to get a written copy of the plan that is developed.***



All of the following individuals must be invited to the conference:

1. The child
2. The child's person in parental relation
3. Other individuals identified by the person in parental relation who may be a resource
4. Appropriate school personnel
5. Recommended service providers

An ***Alternate Attendance Plan*** for a student whose disability impacts attendance can be documented in the IEP or 504 plan to:

- allow the parent to write an excuse versus having to get a medical excuse,
- excuse tardiness, and/or
- avoid disciplinary and truancy consequences.

After a Plan is put into place, medical documentation may be required periodically to verify that the student's condition continues to warrant an Alternate Attendance Plan.

Remember that when your child is absent from school they are missing valuable instruction. When a child is absent due to illness, they may fall behind and this can create stress. Depending upon your child's health circumstances, work with the teacher to maintain a reasonable balance by adjusting expectations, providing extended time, and/or reducing schoolwork to the essentials.

Most importantly, keep lines of communication open with the district and address problems so your child can attend as much as possible.

Resources

Basic Education Circular (BEC) - ***Compulsory School Attendance, Unlawful Absences, and School Attendance Improvement Conferences:***

<https://bit.ly/2BTIDxA>

Education Law Center Fact Sheet - ***Truancy and School Attendance in Pennsylvania:***

<https://bit.ly/3hdwPq7>

School Attendance Improvement Plan Form:

<https://bit.ly/2zkAqS2>

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