



Preparing Students to Manage Health: A Partnership between Home and School

With funding from New York State's Family to Family Health Care Information and Education Center, the information included in this publication was developed to assist families and youth with special health care needs and disabilities.

Taking responsibility and being able to advocate for one's own health care will be different for each person. However, for everyone, **self-direction and autonomy** are desired outcomes.

For parents who have cared for a child and advocated for their child's health care, it is a shift to be guiding a teen or young adult as they move through adolescence towards more independence. Crucial to this is **respecting and supporting an individual's responsibility for their own health care and their participation in decision-making.**

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Parent to Parent of NYS supports and connects families of individuals with disabilities and special health care needs. Every day, the organization hears from caring families and the professionals who support them across the state. For more information about health care and the transition to adulthood or for assistance with any other issues impacting families, please contact us at 1-800-305-8817.

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www.parenttoparentnys.org



TAKING OWNERSHIP OF HEALTH CARE

Tips for parents and caregivers

Are you ready for the day when you take your son or your daughter for a medical appointment and the doctor or medical staff says to you, as the parent or caregiver, “Your young adult is now old enough to talk with me on their own”? What if your son or daughter tells you they are old enough to talk to their doctor on their own?

Are you prepared? Do you think that your son or daughter is prepared to begin self-managing their health and wellness with just your support?

Parents and other caregivers are regularly in charge of their child’s health care. For many parents, the idea that one day their son or daughter may be independent seems impossible, or even impractical. We get stuck in the present. We have difficulty envisioning a future when our children are grown and independent.

The goal for every child is to develop as much independence and self-awareness as they can. How can we help them to be as independent, self-aware, and self-directed about their own health as possible?

What is Taking Ownership of Health Care?

Taking ownership of health care is the process of taking charge of one’s own health care. We all, including children and young adults, need to learn to speak up for ourselves and build a network of trusted individuals ready to assist when needed. Based on varying capabilities, some children may require continued support, possibly significant, as they reach adulthood. For parents and caregivers, we must recognize a person’s inherent desire to be valued as an individual with a unique story, perspective, hopes, and dreams.

The process of taking ownership of health care includes three key components:

1. An awareness of who you are as an individual
2. Knowing your needs and desires
3. Understanding how to work with other people and systems in order to have your needs met

Sometimes these are achieved with the assistance of a network of support that includes parents and others who care.

WHY IS TAKING OWNERSHIP IMPORTANT IN RELATION TO HEALTH CARE?

- Parents and caregivers cannot meet a child's health care needs forever.
- A natural progression in child and youth development is to gradually assume more responsibility for and control over a person's own body. A child's feelings of identity, self-worth, and capability are derived in part from being in control.
- When a person goes to college, post-secondary education or training, a job, independent living or a residential setting, health care needs continue to be an important aspect of daily life.
- To successfully access adult service systems, young adults, to the best of their abilities, need to know their diagnosis, condition, or disability and special health issues, and understand the supports needed.

GETTING STARTED

1. Start at an Early Age

- Maximize opportunities for children to learn about and understand health conditions, treatments, and health care routines.

2. Assess your child's Health-Related Skills and Knowledge

Assess current level of understanding and participation in attending to health care needs

- Discuss medical condition and diagnosis with your child. Advance the conversation over time as a child develops and as age-appropriate. Children are aware of their differences. Children benefit from open discussions that help to identify the tools and supports needed to achieve valued outcomes related to health care.
- Explain health care routines, including treatments and medications, based on the child's development, in age-appropriate ways. Is your child currently directing or participating in the completion of health care routines?
- Explain health insurance and using health insurance cards at appointments.

Explore potential ability to increase participation in health care routines

- Give your child the age-appropriate vocabulary needed to be an active participant. Teach words or alternate communication methods to describe feelings and symptoms. Encourage and provide opportunities for your child to speak and contribute to conversations about health care at the doctor's office, school meetings, clinics, etc.
- Look for signs that indicate your child is ready to learn more about a specific health care condition and take responsibility for some health care routines. Is he asking questions? Is she trying to participate?
- Provide the opportunity for making choices throughout the daily routine to develop decision-making skills. Choices regarding health care routines can be gradually built into this process.

Understanding healthy habits and basic health principles and the effect of special health care needs and disability on individual health decisions

- Model effective partnerships with professionals and help develop trusting relationships with your child's team.
- Discuss general health routines regarding diet, exercise, and rest.
- Start early to teach special considerations warranted by a physical condition.

3. Break down health care tasks

- Medication: Does your child, as a teen or young adult, know the purpose of medication(s)? What happens if a medication is not taken? What if too much is taken? What are the side effects? Can your child call or mail in a prescription refill? Can your child manage picking up a prescription at the pharmacy or make the necessary arrangements?
- Tasks: Can your child describe the tasks and assistance needed? Is your child able to participate in any portion of a treatment regimen by making choices or actually completing part of the task with support?
- Daily routines: Does your child know when something is not right in his or her daily routine? Does your child know how to get help regarding this?

- Appointments: Can your child record a doctor's appointment on the family calendar or keep a log on their computer? Can your child locate his or her doctor's phone number to arrange an appointment or change an appointment?
- School nurse: Is your child responsible for reporting to the school nurse for needed treatments or medications? Can your child learn to do this rather than being called by the nurse or reminded by the teacher?
- Healthy choices: Is your child encouraged to be responsible for healthy choices throughout the day to promote maximum wellness? Can your child make healthy food choices and personal hygiene decisions, and take care of needs related to a specific health condition?
- Self-advocacy: As early as the elementary school grades, create opportunities for your child to practice self-advocacy skills, including self-disclosure and requests for accommodations at Committee on Special Education (CSE) or other meetings.
- Health insurance: Does your child carry their health insurance cards, or copies of them? Do they understand how they are used?

PREPARING FOR TRANSITION FROM HIGH SCHOOL

Use a team approach with your child and other CSE members to ensure that health-related skills are incorporated into the Individualized Education Plan (IEP). Your child needs to learn about health care service systems and to practice how to access these systems to prepare for adulthood. Do not wait until transition age to formally address health care in the IEP.

You and your child know what needs must be addressed for a successful transition. Identify and clearly communicate these needs. Be assertive and advocate. Make sure your child is involved and becomes a self-advocate throughout the school years and beyond.

Additional Resources

The NYS Institute for Health Transition Training
www.healthytransitionsny.org

The Self-Determination Synthesis Project (Comprehensive government-funded synthesis site): The site includes lesson plans and parent resources for the transition-aged adolescent. Includes exemplar program sites and resources for youth. <http://sdsp.uncc.edu/home.asp>

The Youthhood: A site for youth and the adults in their lives. Addresses setting goals and planning for the future. Includes a content section entitled "The Health Clinic" which engages youth in developing an understanding of their health, becoming their own advocate, and understanding health insurance issues. <http://www.youthhood.org/index.asp>

The Beach Center on Disability: The site includes the Arc's Self-Determination Scale for adolescents with cognitive disabilities. http://www.beachcenter.org/education_and_training/self-determination.aspx?JScript=1

Wallet-size portable health record
<http://www.health.state.ny.us/publications/0972.pdf>

Self-Determination Resource Web site – Parent Page
<http://www.selfdeterminationak.org/parents.html>

University of Oklahoma, Zarrow Center on Self-Determination: Includes the AIR Self-Determination Assessments, self-determination educational materials, and resources. <http://education.ou.edu/zarrow/?p=38&z=3>

Wrightslaw Guidance page on self-advocacy: Includes many links to other sites and resources. http://www.wrightslaw.com/info/self_advocacy.htm

In preparation for possible accidents, severe illness, or medical need, all families should consider self-determination in the area of advance directives. http://www.abanet.org/publiced/practical/patient_self_determination_act.html

My Health, My Choice, My Responsibility: A training program to help individuals with developmental disabilities make healthy choices in daily life and speak up for good health.
<http://community.wihd.org/Page.aspx?pid=275>

The Gateway to Self-Determination Web Portal: A clearinghouse on resources, training, and information on self-determination. This site provides a single access for self-advocates, professionals, policy-makers, and the general public on the current best practices and evidence-based activities in enhancing self-determination in the lives of people with developmental and intellectual disabilities, as well as any individual.
<http://www.aucd.org/ngsd/template/index.cfm>



Addressing Chronic Health Care Needs in the IEP

Points to Consider

To ensure successful transition to adult living, learning, and earning, the Individualized Educational Plan (IEP) for students receiving Special Education Services should address any chronic health care conditions that affect their education. Many important changes in legal status, systems of care, and services occur between the ages of 18 and 21. Planning for transitions to post-secondary life must start at age 14 or earlier and should include education for health care responsibility and self-advocacy.

IEP classification categories, such as "Other Health Impairment," convey the presence of an acute or chronic health problem that adversely affects a child's educational performance. However, the classification does not convey specific health conditions, health care needs and the components of an IEP designed to address these needs. Identifying appropriate health-related services and health care education for the transition age student is crucial to the planning process for post-secondary life.

HEALTH-RELATED SERVICES TO ADDRESS HEALTH CARE NEEDS

When developing an IEP, the team must clearly state current levels of functioning, and performance, and current health care status. The IEP identifies services that will enable a student to reach educational goals and addresses health-related services, such as skilled nursing and therapies necessary to enable a student to access and receive a free appropriate public education.

- The IEP communicates health care needs to all involved with the student. The IEP is the foremost communication tool that provides all the educational professionals, medical services providers and paraprofessionals with a clear and comprehensive picture of a student within the school environment. Since students typically have new teachers and related service providers every year, an IEP that includes health care needs serves to increase the understanding of a particular health condition, symptoms, and treatment that may affect the student's school day.
- The IEP should establish health care goals for the student. A student's awareness of health care issues and movement toward self-determination increases safety. Even if a student is not expected to move completely toward independence in self-care, it is important for the student to understand their care routines and question any change, as appropriate.
- The IEP should establish strategies for developing the skills necessary to self-advocate for quality health care and meet health care needs, either independently or with support.
- A student considering working or pursuing post-secondary education has the potential to be self-determined and to self-advocate for his or her needs. This includes the adult domains of living, earning, lifelong learning, and health care. These goals start with the IEP.

MOVING TOWARDS INDEPENDENCE IN HEALTH CARE

Identifying and communicating the need for assistance

When students are concerned about their physical and emotional health and health care, they need to learn:

1. who to contact,
2. what information needs to be conveyed,
3. where to discuss the information in a confidential manner, and
4. how to appropriately convey the information.

Participating in health care and decision making

Accurate, assertive communication leads to better health care and enables a student to be prepared to handle a lifetime of transitions, including new educational and medical staff, new caregivers, and adult housing.

Students with chronic, lifelong health conditions can be taught to participate in their own care. Students can care for and advocate for themselves when they understand their health condition and treatment. Self-knowledge and self-direction are the ability to identify and convey one's own needs, are critical to fostering independence.

Learning about personal, individual health care needs helps students to positively discuss their conditions with others and teach others about their specific condition and needs, building self-knowledge and confidence and gaining respect from others. This promotes trust from others regarding a student's ability and accuracy in conveying information about their symptoms and care routines. Learning and sharing about a condition also demystifies it to the student and others, and helps avoid the stigma that can be attached to a special needs issue.

Frequent opportunities, from a young age, to practice and implement skills that carry over to daily living will build a foundation for successful transition to adulthood. School nurses, teachers, and related service providers can provide collaborative guidance that connects attainable goals to similar tasks in the school setting, helping develop generalized skill sets that can be transferred across settings.

Note: **Self Direction** is a term used to describe the freedom a person has to make their own choices. **Self Determination** is a term used to describe the principle that people have the right to freely choose; determination of one's own fate or course of action without compulsion; free will.

Additional Resources

Check out "Health Care and the IEP, Tips for Students, Parents, Educators"
Developmental Trends: Chronic Health Conditions in Children & Adolescents
<http://www.education.com/reference/article/chronic-health-children-adolescents/>

Health Conditions and the IEP process
http://southeastregionalcenter.org/pdf/Health_objectives_for_Individual_Education_Plans.pdf

What Does Health Have to do With Transition?
http://www.eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/29/e4/2c.pdf



HEALTH CARE AND THE IEP

Tips for Students, Parents, and Educators

Chronic health care needs must be considered as students move towards achieving post-secondary goals. An effective Individualized Educational Plan (IEP) addresses crucial health issues based on a person's individualized needs. Listed below are some tips on how to incorporate health care into an IEP.

Present Levels of Educational Performance (PLEP)

Health care issues or limitations that affect participation in school and extracurricular activities may be incorporated into the Present Levels of Educational Performance (**PLEP**) section of the IEP. Document the need for consideration of medical issues throughout the day, the understanding of and participation in health care routines and the levels of support required.

Examples:

- Identify how the health care needs impact the academic day, including symptoms, side effects of medications, behaviors and emotional needs, adaptive equipment needs, missed classroom time, and transportation.
- Identify how the health care needs impact after-school hours, including assigning and completion of homework and the ability to participate in after-school extracurricular programs, clubs, or sports.

Meeting Needs Identified in the PLEP – The Rest of the IEP

Sections of the IEP that may contain health-related information, goals, and activities are: Accommodations, Curriculum Modifications, Supports and Services for Staff and the Student, including the Related Services Section, and Annual Goals.

If there is an Individual Health Plan (IHP), i.e., a formal written agreement developed with the interdisciplinary collaboration of the school staff in partnership with the student, the student's family, and the student's health care provider(s), determine and document how that plan interfaces with the IEP and what information or skills the student needs to acquire to carry out the IHP.

Upon reaching the age of age 15 and after, the Coordinated Set of Activities (**CSA**) is another mandated section of the IEP where health care needs related to transition activities may be included.

The Transition Age Student and the IEP

The IEP in effect when a student is age 15 should link the PLEPS and other appropriate IEP sections to the required Measurable Post Secondary Goals (**MPSG**) in the areas of Education/Training, Independent Living and Employment.

For the first IEP in effect when a student is age 15, the CSA form should be completed. The IEP team is required to consider the following areas of transition: Instruction, Related Services, Community Experiences, Development of Employment and Other Post-School Adult Living

Objectives, and, as applicable, Acquisition of Daily Living Skills and Functional Vocational Assessment.

- If the Committee on Special Education (**CSE**) agrees that the student needs support for adult living, is not expected to achieve independent living, competitive post-secondary education or employment, or will need agency assistance to reach those goals, the IEP needs to reflect the involvement of appropriate agencies during the transition years and process.
- For a student with substantial health considerations, the secondary program should be geared toward reasonably enabling the student to achieve as much self-care and independent management of health conditions as possible across all work and living situations. When appropriate, daily living skills including personal care and health care should be addressed within the CSA and elsewhere in the IEP. The MSPGs in all areas should be determined based on discussion and assessment that includes school personnel, student and family input.
- A need for related services, such as occupational therapy, physical therapy, skilled nursing, speech, or mobility training, must be considered for all students classified under IDEA, including the student at transition age. For the transition age student who receives related services, the CSA must reflect the activities provided to support the achievement of the MSPG.

Collaboration in IEP Development

- Collaboration is essential in developing a comprehensive and effective IEP. Students, parents, and others, including outside providers working with a student, must be involved in the process.
- With prior parental permission, schools are responsible to reach out to providers involved in the success of the transitioning student and invite appropriate staff to the IEP meeting.
- Parents can help facilitate interagency collaboration by:
 - providing consent for appropriate outside providers and coordinators to attend the IEP meeting
 - requesting the school include outside providers and service coordinators involved with the student to attend the IEP meeting
 - asking specific staff to attend the IEP meeting
 - requesting a written report on the student's progress from a service provider if an invited provider or service coordinator is unable to attend the IEP meeting

Additional Resources

Local NYS Parent Training Center

<http://www.p12.nysed.gov/specialed/techassist/parentcenters.htm>

Regional Transition Specialists

<http://www.p12.nysed.gov/specialed/techassist/rsetasc/tslist.htm> NYSED has established [10 Regional Special Education Technical Assistance Support Centers \(RSE-TASC\)](#) to act as a coordinated statewide network of special education technical assistance centers.

Secondary Transition Individualized Education Program (IEP) Review

<http://www.p12.nysed.gov/specialed/spp/13selfreview.htm>

Health Care Recordkeeping

<http://parenttoparentnys.org/healthcare/healthcare-details/C24/>



FOSTERING RESPECTFUL RELATIONSHIPS IN EDUCATION

Disability Awareness

Now, more than ever, society is recognizing the importance of respecting the individuality of all people. The classroom, school bus, lunchroom, gymnasium, assembly, athletic field, playground and other school environments are places to model, learn, and teach disability awareness and etiquette. When everyone models respect in everyday interactions and when students see this, they too learn to value and admire all people for who they are and what they do.

The messages that leaders and educators convey play an important role in how students react. The fast pace of today's society, including the media and social networking, bombards students with multiple messages. All school district employees have the potential to model pro-active disability awareness messages for students and each other.

Establishing respectful and trusting relationships is fundamental to achieving an appropriate educational environment for all. Children and adults without the experience of living or working with a person with a disability, may not have a frame of reference and may find it awkward or uncomfortable being with a person with disabilities, chronic health care needs or who needs accommodations.

As an educator, creating equal learning opportunities for students with disabilities or chronic health care needs based on respect and understanding is an essential ingredient for their success. Consider building upon or creating opportunities in which students with and without disabilities and chronic health care needs can share positive experiences together. Children are inherently curious and are taught to be observant. If a student comments or asks questions, it is an opportunity for a teaching moment. Treat such inquiries as attempts to better understand or get to know another person from a perspective of informed honesty, openness, dignity and respect.

Guiding Principles: Showing Respect and Building Trust with Students who have Disabilities

Be Prepared: Prepare for an upcoming school year. If there will be a student with a disability or chronic health care need attending your class, prior to the first day of school arrange to meet with the student and family and their advocate as appropriate. The discussion should include the person's needs based on the disability, health care, and medical routines, and any accommodations required. Families may have practical suggestions about strategies to enhance the school environment. Throughout the year, do the same when a student with a disability or chronic health care need is new to your class.

Maintain Confidentiality: Students, parents and advocates need to be assured that information will only be discussed in appropriate settings with the appropriate people and be distributed only as necessary.

Acknowledge Disability: Do not act as if the disability does not exist. Ask clarifying questions. Do whatever you can to limit a student's feelings of isolation and stigma. Treat the student with respect and dignity and expect that others do the same. Define needs based on the disability but omit the diagnosis (unless absolutely necessary) or "label."

Ask Questions with Sensitivity: Ask only those questions that lead to a greater understanding of the student and the issues related to the person's disability. Provide assurances to students and parents that limitations due to the disability are not misunderstood. Listen carefully to statements about medical needs and continue to respect and address stated needs as these arise.

Use "Person First" Language: Language is a powerful tool! Identity is a person's name, not his or her disability. For example, do not identify a person as "the diabetic." Instead, as necessary, refer to a

person as "a student with diabetes." A person's disability does not define who she is, what she can do, and what she needs. Using "person first" language is a subtle but powerful way to shift the focus from the disability to the student. Speak about the person first, not the disability or barriers. Place the focus on abilities and achievements.

Use Positive Language: Avoid negative or limiting terms such as "handicapped bathroom" or "confined to a wheelchair." Use enabling and empowering language, such as "accessible bathroom" and "the person uses a wheelchair." Set the tone in the classroom and convey a positive message about the acceptance and treatment of students with disabilities.

Clarify Expectations: Ensure that a student with a disability is aware of the expectations of the class, including required coursework and student responsibilities. Work with the student to provide appropriate consideration to any modifications and accommodations as required by an Individualized Education Plan (IEP) or a 504 Education Plan.

Provide Adequate Personal Space: Students who use medical equipment or devices should be given the same personal space as students without disabilities. Mobility or medical equipment are part of the personal body space of the individual who uses it. Respect the need for adequate personal space. Be respectful of a person's privacy. Expect this of all who interact daily with the student.

Respect Decisions: How much and when to disclose a disability is up to the student and should be respected by all. The student and educators should decide how peer education and involvement might enhance or detract from the student's success in the school environment.

Awareness of Multiple Service Systems: Students with disabilities and their families interact with multiple service systems, professionals and agencies. Navigating these systems, with varying terminologies and requirements, can be overwhelming and confusing. Be cognizant that each system places numerous and conflicting requests and demands upon students and parents, multiplying stress levels and anxieties. Keep this in mind when placing expectations on the student and the family.

Seek Out Proper Medical Advice: Students with disabilities or chronic health care needs often have complex medical issues. Assume that specific regimens have been implemented for good reason. Offering your own advice, while well intentioned, can add undue stress and feelings of being misunderstood. Ask clarifying questions and enlist the help of trained professionals when medical issues arise.

Offer Objective Observations: Be conscious of what is happening to a student during the entire school day. Communication with the school nurse, other professionals and family members leads to better care and prevention of complications that could alter the person's educational goals.

Additional Resources

Kids Together Inc. - People 1st Language; Inclusion, Freedom, and Respect for all. A commentary by Kathy Snow. <http://www.kidstogether.org/pep-1st.htm>

Disability World - Teaching Kids Disability Etiquette.

<http://www.disabled-world.com/disability/awareness/disability-etiquette.php>