

Setting Health Goals

Moving from Pediatric to Adult Health Care

Continuing Education Module



healthy
transitions



healthytransitionsny.org

✓ Learn ✓ See ✓ Do

Skills for Moving from Pediatric to Adult Health Care

- Scheduling an Appointment
- Getting Health Insurance
- Deciding About Guardianship
- Speaking up at the Doctor's Office
- Understanding Your Disability
- Managing Medications
- Keeping a Health Summary
- Looking into Service Coordination
- Setting Health Goals
- Finding Community Resources

Welcome!

This education module provides information that families and professionals can use to help youths who have developmental disabilities to set health goals.

Setting Health Goals:

Skill attainment for this topic is defined when the adolescent or young adult is able to:

- ✓ Name a health goal, or choose a health goal from a list
- ✓ Talk about his/her health goal in own words
- ✓ Assemble friends and family members who can help (“Circle of Support”)
- ✓ Take steps that are needed to reach a health goal with the help of his/her “Circle of Support”
- ✓ Monitor progress toward achieving the health goal with the help of his/her “Circle of Support”

This continuing education module is part of a 10-unit curriculum that was developed for families, health care providers, service coordinators and other professionals who would like to facilitate the transition from pediatric to adult health care for youths who have developmental disabilities. Adolescence and young adulthood is a time of tremendous change, not just physically, but also in terms of social and emotional development, and due to transitions in services, supports and health care providers. The Healthy Transitions curriculum provides a context for mutual understanding and collaboration during this complex time.

The curriculum is organized around 10 key skills that youths need to develop in order to transition to adult health care. The skills are not sequential. They can be developed over time, between the ages of 14-25 years. The Healthy Transitions checklist (see “script pad”) can be used to track accomplishments. Each module provides strategies that families and professionals can use to help youths to develop a particular skill. The curriculum emphasizes self-determination and the active involvement of young adults who have developmental disabilities in their own health care.

The modules begin with a vignette that illustrates a transition “success story”. This is followed by didactic information and a list of references and resources for skill development. A table with “tips for collaboration” lists concrete steps that youths, families, service coordinators, and health care providers can take in order to facilitate the transition process. A self-assessment quiz is included at the end of each module.

In addition to the Continuing Education Modules, the Healthy Transitions project offers Lessons Plans, Videos and a Moderator Guide for educators that can be used in group settings with young adults. Our website also features a secure network of personal health sites called **MY PLACE** that link youths to a personal transition team for care coordination, planning, and setting priorities during the transition to adulthood.

Please visit us at HealthyTransitionsNY.org to find out more. We welcome feedback!

Darcy

Darcy is a 24 year old woman with multiple disabilities who has gained nearly 50 pounds since she transitioned to the adult health care system. Her mother, Pat, initially ran into some complacency about this situation. Darcy's adult health care providers did not recognize Darcy's weight gain as a distinct health concern. Many attributed the obesity to Darcy's mobility impairment and her underlying developmental disability. Pat shared her concern that obesity was not "natural" for Darcy. Thanks to Pat's advocacy, Darcy's nurse practitioner calculated Darcy's Body Mass Index. She recognized and accepted that Darcy had a weight problem, and put an action plan into place.



Darcy's nurse practitioner contacted the Office for People with Developmental Disabilities (OPWDD) and requested an evaluation from a nutritionist. Darcy worked with the nutritionist to come up with a diet plan that would accommodate her hunger, social eating habits, as well as "quirks". Darcy chose her diet plan by reviewing a food pyramid with the nutritionist. Together they made a weekly grocery list. They also created a chart to monitor how frequently Darcy exercises and to periodically record Darcy's weight. The nutritionist also conducted an in-service with Darcy's day habilitation staff, many of whom had been offering Darcy snacks between meals. Consistency about mealtime routines was sought, pictures of portion sizes were distributed, reminder sheets were posted, and ideas for successful strategies and "distraction" methods were shared.

Darcy's OT, PT, Recreational Specialist, and day-habilitation staff were also included in planning activities. Darcy switched back to using her walker, rather than relying on her wheelchair. She started a twice-weekly aquatic therapy program and also enjoys horseback riding and bicycling in the community. Darcy has lost 20 pounds so far. Darcy's health and quality of life have improved substantially since setting weight loss as a health goal.

Setting Health Goals Learning Objectives:

1. Define self-determination
2. Define “learned helplessness”
3. Give examples of health goals that are relevant to youths who have developmental disabilities during the transition years
4. List four steps that foster self determination when setting health goals
5. Name three community resources available to youths with developmental disabilities who are interested in joining a wellness program



Learning Objectives

This module will focus on strategies that families, service coordinators and health care providers can use to help youths with developmental disabilities to set health goals. The context for this topic, and a central theme for the entire Healthy Transitions curriculum is self-determination.

Self-determination

Self-determination is a theory about motivation that was developed in the 1980s by social science researchers Edward L. Deci and Richard M. Ryan. It has been applied to a wide variety of settings. In particular, self-determination theory has revolutionized the field of special education. Self-determination is defined as a combination of attitudes and abilities that leads people to set goals for themselves and to take the initiative to reach those goals. Dozens of curricula have been developed to enhance self-determination for students with disabilities. When compared with conventional special education curricula, students graduating from self-determination programs are more successful in making the transition to adulthood as measured in terms of employment and independent living. Self-determination also holds great potential for improving health outcomes for youths with developmental disabilities.

Learned helplessness

In the context of health care, self-determination is the opposite of “learned helplessness.” Learned helplessness is a phenomenon that has been well described in the medical literature. It is best encapsulated by the common scenario of a doctor or nurse who directs all conversation to the parent, rather than the young adult patient. This is a cue to the adolescent that it is ok to be passive. Over time the adolescent “learns” to be “helpless” during health care encounters. This is often unintentional, and may be due to many factors.

“Letting go” in order to give adolescents who have developmental disabilities autonomy during a health care visit is a delicate topic for both families and health care providers. There is a very natural tendency for all involved to be protective. The reality is that most families have had to develop strong advocacy skills over the years, to assure that high quality medical care is provided. Yet it is critical during adolescence that parents and health care providers give youths the opportunity to demonstrate, both to themselves and to others, that they are capable of active involvement in their own health care. Self-determination can only be learned from real world experience (including mistakes) and an open, supportive acknowledgement of disability. This way, youths enter the adult health care system with the skills that are needed to navigate services and to engage in meaningful discussions. When viewed in this light, the transition to adulthood isn’t so much about “letting go” as it is about “creating opportunities” for youths to develop skills and for parents to be pro-active and future oriented. Health care encounters that emphasize self-determination (as opposed to learned helplessness) focus explicitly on engaging the youth in his/her own health care.

Self-determination and health goals:

When applied to the setting of health goals, self-determination is a process that involves:

- **Choosing a health goal**
- **Expressing the health goal**
- **Taking the steps needed to reach the health goal**
- **Following up to make sure the health goal is accomplished**

How can health care providers, service coordinators, and family caregivers foster self-determination? A 4-step process is outlined in the chart on the next page:

Fostering Self-Determination

1. Choose

It can be extremely helpful to begin a health care encounter with a general discussion of health goals that are relevant for the youth, such as self care skills or the prevention of obesity or other secondary (i.e. preventable) conditions. Open-ended questions may be appropriate for some individuals. For others it may be better to provide a list of goals and ask the young adult to choose a goal from that list. Making a choice is consistent with self-determination in that it requires the young adult to be actively engaged.

2. Express

The next step is “expressing the goal.” This literally means asking the youth to state and talk about his/her health goal, in his/her own words. A very simple way to foster this is for health care providers to speak directly to the young adult patient, to give the youth the time that is needed to respond, and to maintain eye contact with the youth during the conversation. This does not mean that parents are excluded from discussion. On the contrary, family caregivers and/or other members of a youth’s “Circle of Support” can help the youth to “open up” because they are familiar with the youth’s communication style, and because they provide security and trust during the health care encounter. Once the youth is engaged, family members step back and listen. A video entitled “*Acknowledge Circle of Support*” demonstrates how a sensitive and supportive parent encourages her daughter to express herself: http://healthytransitionsny.org/skills_media/video_show. Most youths quickly become comfortable with being the focus of attention. Some require more encouragement than others to speak up. All youths benefit from the opportunity to practice self-expression during each and every health care visit. A basic tenet of self-determination is to learn by doing. .

3. Take Steps

Once the youth has expressed his/her goal, the health care encounter can focus on the steps that will be taken to accomplish the stated goal. This is where it is important to have an open and honest discussion about disability. Ask the youth, “Can you do this by yourself, or are there people from your Circle of Support who can help?” Giving the youth the responsibility to decide who can help keeps the process self-determined. The steps that will be taken to accomplish a goal are similar to action plans used in disease management programs such as for asthma care and diabetes care. An action plan is a written document that describes the steps that the youth and his/her Circle of Support will take to accomplish a health goal. An action plan identifies discrete steps that are realistic, measurable and attainable. An example is provided in the video entitled “*Self Determination and Health*” at http://healthytransitionsny.org/skills_media/video_show. In this vignette a day habilitation provider helps a young woman who has a developmental disability to identify the steps that she will take to lose weight. Together they review a food pyramid chart. The young woman **chooses** foods from this chart, and **expresses** herself by making a grocery list. The day habilitation provider uses principles of self-determination to help the young woman to **identify the steps** that are needed for goal attainment.

4. Follow Up

Last but not least, the health care encounter should provide the youth with tools for monitoring his/her progress. Setting a health goal is not an open-ended exercise. It requires accountability of both the physician and the patient. This is accomplished by systematically tracking accomplishments (for example, a chart for documenting weight loss, or a peak flow meter for measuring asthma control) and with dedicated office visits or phone calls to monitor progress and make adjustments. Studies have shown that accountability improves when a patient has a consistent relationship with the person who is helping to monitor progress. That person can be a nurse, other office staff, or even a day-habilitation provider, and does not necessarily need to be a physician.

Goal-setter Tool

A goal-setting tool that incorporates **the four-steps towards fostering self-determination** is available at HealthyTransitionsNY.org (http://healthytransitionsny.com/skills_media/tool_show). The goal-setter can be downloaded, printed, or archived on a secure personal health site called **MY PLACE** at Healthy TransitionsNY.org (https://healthytransitionsny.org/healthy//my_dmsn/index). The goal-setter fosters self-determination by prompting youths to set goals, to identify people who can help along the way, and to list the steps that will be needed for goal attainment. Email updates can be sent from **MY PLACE** to health care providers and/or other members of the youth's Circle of Support. This allows all involved to monitor progress, and assures accountability. The screen shot below illustrates how Darcy and her mother (featured in the vignette at the beginning of this module) used the goal setter on Darcy's **MY PLACE** site to develop an action plan for Darcy.

healthy transitions Moving from Pediatric to Adult Health Care

My Place:

- Team
- Forms
- Goals
- Calendar
- Discussion
- Profile

Select

- My Place Handbook
- Terms of Use
- Privacy Policy
- Profile
- Print
- Logout

VeriSign Secured

Goal: **Weight loss (BMI goal: 25)**

Steps:

1. get script for diet and set BMI goal with Dr. D. ✓
2. evaluation by Jeannette W. (UCP nutritionist) ✓
3. inservice at IRA with Jeannette W. and Pat ✓
4. monthly weight checks by Kelly N. (nurse for IRA) Click Here
5. horseback riding with Carrie E. (PT) & Nora S. (recreation) Click Here

SAVE PRINT Email TEAM Email Circle

New York State Institute for Health Transition Training for Youth with Developmental Disabilities Ages 14-25 Years, Families, Service Coordinators, and Health Care Providers

UPSTATE MEDICAL UNIVERSITY UPSTATE Golisano Children's Hospital NEW YORK STATE Developmental Disabilities Planning Council

Health Goals During the Transition Years

Examples of health goals that may be relevant to youths who have developmental disabilities during the transition years are listed below:

- **Hygiene** (Example: Remembering to brush and floss teeth every day)
- **Self Care** (Example: Taking medications on schedule)
- **Prevention of Secondary Conditions that are Specific to a Disability** (Example: Adolescent with spina bifida learning how to do skin checks to prevent pressure sores)
- **Wellness** (Example: Developing a regular exercise program to stay fit and be active in the community)

Lifestyle changes are often necessary in order to attain a health goal. For example, effective weight loss programs require people to change their shopping and cooking habits, and to make time for regular exercise. Lifestyle changes such as these can be accomplished more easily if they are done within a supportive social context. Social support is absolutely essential to the success of health and wellness initiatives for young adults who have developmental disabilities. Social support and community resources should be explicitly discussed when setting health goals with young adult patients who have developmental disabilities. The goal-setter tool (http://healthytransitionsny.com/skills_media/tool_show) can be used as a template to identify a Circle of Support during these discussions. Information and referral to agencies and services in the community is also essential.

Many communities offer day habilitation programs that focus on wellness, such as cooking classes, and hiking groups. These are typically funded by the Office for People with Developmental Disabilities (OPWDD). Medicaid service coordinators can provide information and facilitate enrollment. The Special Olympics “Healthy Athletes” program (http://www.specialolympics.org/healthy_athletes.aspx) and the local YMCA (<http://www.ymca.net/about-us/>) are also great resources. School nurses, health educators, physical education teachers, and teachers of life-skills classes at school can also help to identify or to develop a wellness program. Wellness programs based on principles of universal design should also be explored. Many youths prefer to simply join a local gym or groups such as Weight Watchers, where disability is not a pre-requisite for enrollment.

Several health and wellness curricula for youth who have developmental disabilities are available on the Internet. The Westchester Institute for Human Development and the Self Advocacy Association of New York have created an excellent series of wellness seminars for youths with developmental disabilities called “My Health, My Choice, My Responsibility.” These seminars can be used by groups of 8-10 youths in day habilitation programs, classrooms, or other small group settings (<http://community.wihd.org/Page.aspx?pid=339>). Topics include nutrition, physical activity, safety, hygiene, and emotional health.

The Healthy Transitions project has created a moderator guide and 40 video vignettes that illustrate various health related skills: (http://www.healthytransitionsny.org/skills_media/video_show). Six lesson plans about health care transition can also be downloaded from the HealthyTransitionsNY.org website (http://www.healthytransitionsny.org/skills/show_all). These materials were designed to be used in small groups so that youths can share experiences and ideas and provide support to one another, consistent with principles of self-determination.

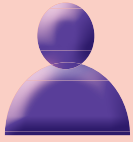
In Summary

Self-determination is a basic tenet of successful health care transition. When applied to the setting of health goals, self-determination is a process that involves:

- **Choosing a health goal**
- **Expressing the health goal**
- **Taking the steps needed to reach the health goal**
- **Following up to make sure the health goal is accomplished**

Social support and community resources should be explicitly discussed when setting health goals with young adults who have developmental disabilities. Resources available in most communities include the Office for People with Developmental Disabilities (OPWDD), YMCA, and schools. Wellness curricula that can be used in small group settings include “My Healthy, My Choice, My Responsibility” (<http://community.wihd.org/Page.aspx?pid=339>) and the “Healthy Transitions” lesson plans, videos, and goal-setting tool available at www.HealthyTransitionsNY.org.

Setting Health Goals Tips for Collaboration



**Adolescent/
Young Adult**

- Make a list of health goals that are important to you. Talk with your doctor or nurse about these goals.
- Decide if you need help to accomplish your health goal, and if so, create a “Circle of Support” (people who can help you).
- Keep track of your progress on a calendar, chart, blog or diary, or by using the goal-setter tool (available at HealthyTransitionsNY.org).
- Join a club or group that focuses on wellness or use resources at HealthyTransitionsNY.org (videos, lesson plans) to start a wellness group.



Family

- Encourage your son/daughter to ask about health and wellness at the doctor’s office.
- Help son/daughter to define steps that will be needed to accomplish a health goal.
- Encourage son/daughter to reach out to friends and supporters in the community when developing a “Circle of Support” for a health goal.
- View your son/daughter’s increasing autonomy at health care visits in a positive light. “Stepping back” as a parent is an opportunity to be proactive and future oriented, and not just a matter of “letting go.”



**Health Care
Providers**

- Give youths a list of health goals to choose from (for example goals for improving hygiene and self-care, for preventing secondary conditions, or for promoting wellness).
- Encourage youths to talk about their health goals.
- Schedule a follow-up visit to discuss progress and/or roadblocks to achieving a health goal. Be accountable!
- Always give your patients a way to track progress toward achieving a health goal (for example, a target weight when starting a weight loss program).
- Identify someone from the health care team who will be available consistently to monitor a youth’s progress toward achieving a health goal.

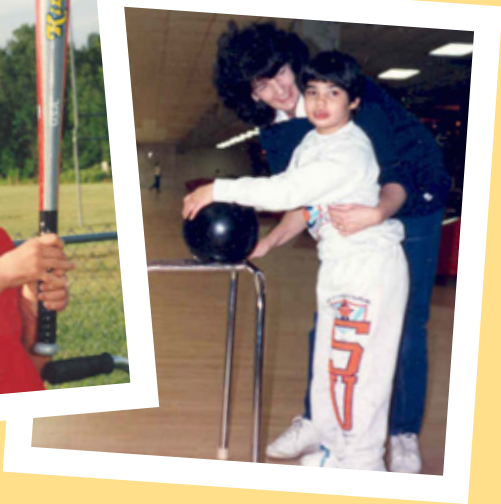


**Service
Coordinators**

- Use the goal setter tool at HealthyTransitionsNY.org to help a youth set his/her health goals and to identify a “Circle of Support”.
- Help youth to define the steps that will be needed to accomplish a goal.
- Review progress toward achieving a health goal at every meeting.
- Provide information about community resources for promoting health and wellness.



Darcy



References and Resources

Website for Self-Determination Theory, University of Rochester

Information about research, best practices, conferences and more

<http://www.psych.rochester.edu/SDT/>

Self-Determination Synthesis Project, University of North Carolina at Charlotte

A complete listing of self-determination education curricula

http://sdsp.uncc.edu/sd_curricula.asp

TASH

Advocacy for equity, opportunity and inclusion for people with disabilities since 1975

<http://www.tash.org/index.html>

The Center for Self Determination

<http://www.centerforself-determination.com/>

Self Advocacy Association of New York State

<http://www.sanys.org/>

Centers for Disease Control and Prevention Disability and Health web resource

<http://www.cdc.gov/ncbddd/disabilityandhealth/index.html>

National Center for Physical Activity and Disability

<http://www.ncpad.org/>

Special Olympics “Health Athletes” initiative

http://www.specialolympics.org/healthy_athletes.aspx

The Y- national website of the YMCA

<http://www.ymca.net/about-us/>

“My Health, My Choice, My Responsibility” curriculum

Westchester Institute for Human Development

<http://community.wihd.org/Page.aspx?pid=339>

HealthyTransitionsNY.org videos and moderator guide

http://healthytransitionsny.org/skills_media/video_show

HealthyTransitionsNY.org lesson plans

http://healthytransitionsny.org/skills/show_all

HealthyTransitionsNY.org goal-setter tool

http://healthytransitionsny.org/skills_media/tool_show

MY PLACE personal health sites at HealthyTransitionsNY.org

https://healthytransitionsny.org/healthy//my_dmsn/index

Quiz

1. What is Self-Determination?

- a. A combination of attitudes and abilities that leads people to set goals for themselves and to take the initiative to reach these goals.
- b. An insurance waiver program available to people with developmental disabilities in New York State.
- c. A type of Individualized Education Plan available to adolescents with developmental disabilities between the ages of 18-21 years.
- d. A sub-section of the Americans with Disabilities Act.
- e. An alternative to the Call-A-Bus program.

2. Select the scenario that illustrates “Learned Helplessness”

- a. A 20-year old who has an intellectual disability waits for his mother to ask questions at the doctor’s office.
- b. A teenager with cerebral palsy describes side effects of her medications to her nurse.
- c. An adolescent with Autism practices shaking hands with his doctor at every office visit.
- d. The parent of an 18-year-old young man with spina bifida sits in the waiting room during a health care encounter.
- e. A young woman with Down Syndrome makes a list of questions she would like to ask before going to a medical appointment.

3. Which health goal(s) is/are most relevant during the transition to adulthood?

- a. Having good hygiene
- b. Developing self care skills
- c. Preventing secondary conditions
- d. Starting a wellness program
- e. All of the above

4. Four steps that foster self-determination when setting health goals are:

- a. choosing a health goal, expressing the health goal, taking the steps that are needed to reach the health goal, and following up to make sure the health goal is accomplished
- b. prioritizing health, reviewing medications, discussing transition to adulthood, and keeping a health summary
- c. being able, affable, available, and having an accessible office
- d. establishing guardianship, discussing transportation, reviewing medications, and keeping an insurance card
- e. none of the above

5. Community resources available to youths with developmental disabilities who are interested in joining a wellness program include

- a. YMCA
- b. Office for People with Developmental Disabilities (OPWDD)
- c. Local Gym
- d. High School Adapted Physical Education program
- e. All of the above

Answer key: 1(a); 2(a); 3(e); 4(a); 5(e)

Notes

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