Healthy Transitions Videos

Moderator Guide

healthy transitions

Moving from Pediatric to Adult Health Care

HealthyTransitionsNY.org

Healthy Transitions Videos

Moderator Guide

Dear Educator,

This moderator's guide accompanies a series of 40 video vignettes that were made with, and for, young adults with developmental disabilities. The vignettes depict situations that occur in real life and demonstrate skills that young adults can develop in order to become more actively involved with their own health care. This moderator guide provides the basic information that group leaders will need to teach and/or learn the main points for each video vignette. The videos are organized topically into 10 skill areas:

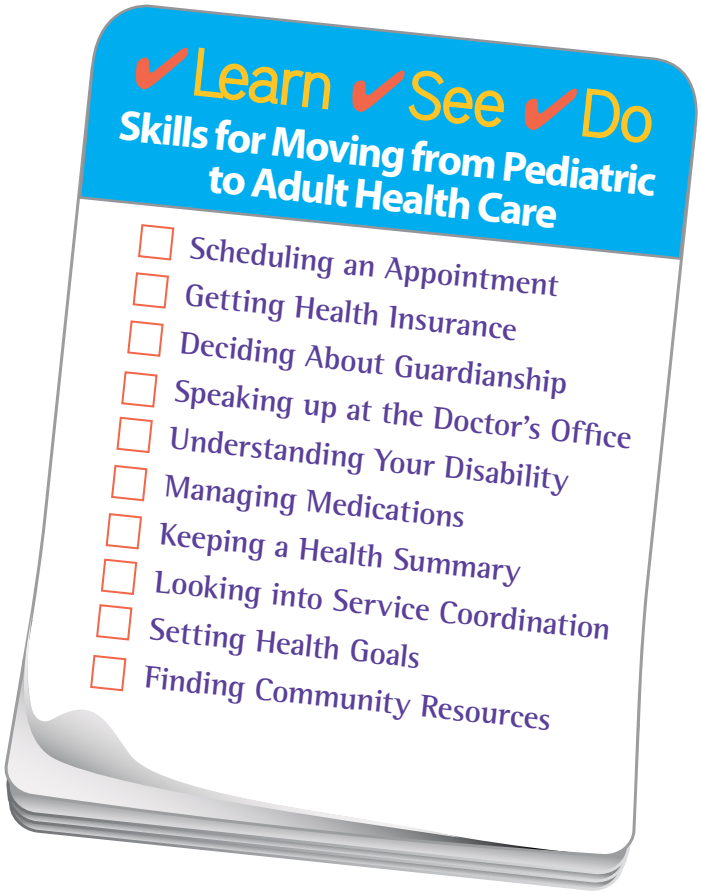
1. **Scheduling an appointment**
2. **Getting health insurance**
3. **Deciding about guardianship**
4. **Speaking up at the doctor's office**
5. **Understanding my disability**
6. **Managing medications**
7. **Keeping a health summary**
8. **Looking into service coordination**
9. **Setting health goals**
10. **Finding community resources**

This guide follows the vignettes closely and outlines for the moderator the main points for each vignette. Each point provides an opportunity for the moderator to pause the video and facilitate discussion. Questions for group discussion are provided at the bottom of each page. The videos use modeling and role play to promote independence with various health related skills. They also focus on self-determination and self advocacy. The videos are brief (2-3 minutes) and can be viewed individually or in sequence according to skill topic. Several of the videos are also incorporated into lesson plans that can be downloaded from our website.

The Healthy Transitions videos and moderator guide are designed for group sessions with an instructor and 5-15 young adults with developmental disabilities. Group size is always something to consider. Groups that are too small or too large can be inhibiting when it comes to discussions. The compatibility of the group is also an important aspect. It is important to have people within the group who are comfortable discussing issues brought up by the curriculum, but sometimes one or two people can dominate the discussions. It is important to take notice if someone in the group dominates. If this happens, the group leader needs to establish some guidelines for the group to follow to assure all members get a chance to be heard. The person who dominates may not understand that he or she is doing this, so it is important to handle this type of situation in a diplomatic manner. Because this curriculum is about self advocacy, ask the group how to handle the situation without pointing out anyone as a culprit. Tell the group you are interested in everyone's opinions and insights, and ask how you should proceed to assure that everyone has a chance to speak. Having youths participate as co-leaders is another strategy to consider.

Social support is something we all need. That is why we designed these videos and the moderator guide to be used by groups of young adults. Most people need encouragement and support to accomplish the goals they have set up for themselves. This is particularly true for health goals that require lifestyle changes such as losing weight and eating a healthy diet. People who experience good social support tend to be emotionally and physically healthier than those who do not have this. Creating groups around interests is a great way to bring people together. For example, many people enjoy book clubs, where the focus of the group is a book they are all reading. There are running clubs, motorcycle clubs, quilting clubs and so on. This curriculum can be used in classrooms, day habilitation programs, or it can function as a focus for an informal club. One of the areas many people with a disability report difficulty with is making friends, and keeping friendships going. This curriculum provides the tools for creating relationships around the focus of health and advocacy.

This moderator guide, the 40 video vignettes, and the six lesson plans can be downloaded from the Internet at HealthyTransitionsNY.org. We also offer a 10-part series about health care transition for parents and professionals. Finally, HealthyTransitionsNY.org features a network of secure personal health sites called **MY PLACE** that can be used to link youths to a personal transition team for care coordination, planning, and setting priorities during the transition to adulthood. Please visit us on the Internet to find out more. We welcome feedback!



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Please contact us at www.HealthyTransitionsNY.org if you have any questions or suggestions for improving the curriculum. We welcome feedback!

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Video Guide 1: Scheduling a Medical Appointment

In this vignette a young man with spina bifida demonstrates how to make a phone call to schedule a medical appointment. Step by step instructions are provided. It may be necessary to view the vignette several times. Go over each point individually in order to promote independence with this task.

1. **"Have ready..."**
   Find out where the person keeps his/her important phone numbers, insurance cards etc., and if she/he cannot tell you where, help him/her to create a log. Important phone numbers should be kept in a place that is readily accessible to the person: in a wallet, handbag or in a special location set up specifically for this purpose. Having special places for important information is necessary for record keeping. Discuss where the person could keep this information.

2. **"Say who you are...Say why you need the appointment..."**
   Explain the difference between a routine appointment and a visit that is scheduled for a specific reason. Go over some of the common reasons people need to see their physicians.

3. **"You might be asked..."**
   Most people cannot remember when they last saw their doctor, so they need to look this information up before making the call. People need to remember to have their insurance card available before they make the call. The moderator can encourage people to keep an appointment log or medical journal with a list of all appointment dates for quick reference. Include all doctors' names, phone numbers, and insurance information in the front of the log, for easy access.

4. **"Repeat back..."** Recording the date and time accurately is not as easy as it seems. This is an area where many errors can occur. Practice listening and writing at the same time. The person with a disability might need to ask the person to whom they are speaking to talk slowly. It's important to repeat back the date and time, to assure accuracy.

Questions for Group Discussion

- **What do you need to have ready before calling to schedule a doctor's visit?**
- **Name two reasons for scheduling a medical visit.**
- **Have you ever called a doctor's office to schedule your own medical appointment?**

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Video Guide 2: Scheduling Transportation

This vignette shows a young man with spina bifida arranging transportation for one of his medical appointments. His sister provides support. Options discussed include asking a family member or a friend, contacting the service coordinator, and calling a taxi company. The phone call to schedule a taxi is portrayed.

1. **"Have ready. . . "**
   It is necessary to have important information on hand before making a phone call. Go over where this information is kept, and/or how participants can get this information before making a phone call. The phone numbers of transportation providers and support people can be added to a "medical log" in an address book, calendar, or agenda.

2. **"How will you get to your appointment?"**
   Many people are anxious about doctor's appointments. This is a great time to discuss the importance of support. Ask participants to discuss how their circle of support can help them to schedule medical visits and transportation.

3. **"Making the phone call . . . "**
   This part of the vignette demonstrates exactly what is said when making a phone call to schedule transportation. This information may seem very basic, but when we are on the phone and under pressure, it is very easy to forget what we need to say and do. A checklist is one way to assure that all information is both retrieved and conveyed. It is especially important to practice these tasks. Practice gives comfort and comfort relieves uncertainty. Discuss role play as a strategy for skill development. Discuss how skill attainment promotes independence.

Questions for Group Discussion

- **Where do you keep phone numbers & contact information for arranging transportation?**
- **Name three ways to arrange for transportation to a medical appointment.**
- **Have you ever arranged for transportation to a medical appointment?**

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Video Guide 3: Paperwork at the Sign In Desk

This vignette provides the viewer with information about paperwork that is exchanged when signing in for a medical appointment. The concepts of Consent to Diagnose and Treat, the HIPAA Law, and Health Guardianship are presented. An individual with a disability and her mother walk the viewers through the process.

1. **A doctor's appointment starts with introductions.** A receptionist should greet patients when they arrive for a medical appointment. The receptionist should greet all members of the party.

2. **The Consent to Diagnose and Treat Form** gives the medical staff at the office permission to examine the patient, make a diagnosis and treat that diagnosis. If the patient is not old enough to sign for him or herself, then a parent or legal guardian can sign for him or her. Not just any adult is able to sign this form. It must be a parent, guardian or someone legally designated to give permission. The patient or the parent will be asked to sign this form, date it, and state what relationship the person signing has to the patient. If the person with a disability is older than 18 years but is unable to sign for him or herself, a parent can legally sign only if he or she is that person's legal guardian or health guardian.

3. **The next form is a HIPAA Form.** HIPAA stands for Health Insurance Portability and Accountability Act. The form is designed to protect the patient, and allows the patient to designate who can have access to his or her medical information. Typically a patient allows the doctor's office to share information with the patient's insurance company. Only those people or organizations designated on the form can have knowledge about the patient's diagnosis and treatment. A patient's parents cannot assume that once the child turns eighteen they will automatically have control over decisions regarding health care. Even parents can be excluded from access if they are not designated on the HIPAA form. This is confusing to many parents. If the child is unable to make decisions for him or herself, the parent needs to petition the court for full guardianship or for health guardianship. See unit on "Deciding about Guardianship."

4. **The doctor's office will want to make a copy of the patient's current insurance card.** It is important to bring insurance cards, legal guardian papers, or health care proxy to all medical appointments.

Questions for Group Discussion

- **Name two forms that patients are given when they sign in for a doctor's visit.**
- **Does anyone have their insurance card with them today?**
- **Have you ever signed paperwork at your doctor's office?**

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Video Guide 4:
Is the Doctor's Office Accessible?

In this vignette an adolescent with cerebral palsy arrives for a medical appointment at a health care facility that does not meet standards for universal design under the Americans with Disabilities Act. The vignette illustrates why it is important to ask about accessibility when scheduling a medical appointment.

1. **"Arriving at the doctor's office...."**
   The adolescent in this vignette encounters several architectural barriers that limit her ability to independently navigate to her doctor's appointment: (a) the elevator buttons are out of reach, (b) the doorway lacks an activation switch, and (c) the countertop at the sign in desk limits her ability to interact with the receptionist. Discuss the ways in which architectural barriers such as these can prevent an adolescent from becoming independent with his/her own health care.

2. **"When scheduling a medical appointment be sure to ask . . ."**
   Explain that many doctors offices do not meet standards for universal design under the Americans with Disabilities Act because this law applies to renovations and new structures only. Bring up other types of barriers, such as those encountered by patients who have vision impairment or patients who are deaf. Discuss why it is important to ask about accessibility when scheduling an appointment with a medical provider.

Questions for Group Discussion

- **What things did you notice that showed that the doctor's office was not accessible?**
- **What is the name of the law that states that doctor's offices must be accessible?**
- **Have you ever been someplace that is not accessible? How did you handle this?**

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Video Guide 5:
Preparing for an IV or Blood Draw

Strategies for reducing anxiety and limiting discomfort during an IV or blood draw are presented in this vignette. A young woman with Down Syndrome prepares for IV placement at home, and discusses what to expect with her mother. Strategies that can be used to limit anxiety during the procedure are also demonstrated.

1. **"Here are some ideas . . . "**
   Anxiety about an IV or blood draw is very common. Strategies for reducing anxiety are discussed. These include asking the doctor for a sedative and/or numbing cream.

2. **"Talk about it . . . "**
   The mother openly and honestly discusses what will happen during an IV or blood draw. The vignette underscores that honesty builds trust, and trust alleviates anxiety.

3. **"Limit wait time"**
   Strategies that can be used to limit anxiety at the doctor's office are presented. These include: (a) limiting wait time, (b) comfort holds, (c) distraction, (d) sedatives. Discuss whether these strategies have been used by anyone in the group. Ask the group to consider other strategies that might alleviate anxiety and discomfort with an IV or blood draw.

Questions for Group Discussion

- **What are things you can do at home to prepare for an IV or blood draw?**
- **Name four strategies that can be used at the doctor's office to limit anxiety.**
- **Have you ever had your blood drawn?**

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Video Guide 6: Preparing for an Operation

In this vignette a young woman with Down Syndrome prepares for an operation by discussing what to expect and by role play with stethoscope, mask, and gloves. General strategies for minimizing stress and anxiety are presented as well.

1. **"Get a sneak peak..."**
   Video footage of the hospital environment, including the operating room and recovery area, is presented. The narrator suggests getting a "sneak peak" by taking a tour or looking at the hospital website. Knowing what to expect can alleviate anxiety.

2. **"Avoid sensory overload..."**
   The hospital environment can be loud and busy. This can easily overwhelm a patient who is sensitive to loud noises or bright lights. This is an excellent opportunity to discuss sensory issues. Ask the group to discuss strategies for minimizing discomfort.

3. **"Role play..."**
   Unfamiliar items that are used in the operating room, such as masks and gloves, can cause anxiety. The vignette demonstrates how role play can build familiarity and alleviate uncertainty.

3. **"Talk about it..."**
   Talking openly and honestly about the operation builds trust. Visual schedules can help patients to understand what to expect.

Questions for Group Discussion

- **What are some ways to prepare for an operation?**
- **Describe what you might see and hear in the operating room.**
- **Have you ever had an operation?**

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Video Guide 7:
On the Day of Surgery

Strategies that can be used by hospital staff to minimize anxiety and discomfort on the day of surgery are presented in this vignette. Scenes include the holding area, the operating room, and the recovery area.

1. **"Preparation in the Holding Area..."**
   The holding area is the place where patients wait before going into surgery. Explaining what will happen, and allowing patients to inspect items such as a blood pressure cuff and stethoscope, helps them to have a sense of control in this setting.

2. **"In the Operating Room..."**
   The vignette shows the sights and sounds that are experienced by patients in the operating room. Minimizing over stimulation is an important strategy for preventing anxiety in the operating room.

3. **"In the Recovery Area..."**
   The vignette shows a young woman with Down Syndrome recovering from surgery. Her parents are with her. This is an excellent opportunity to discuss how family and friends can support someone during a hospital stay.

Questions for Group Discussion

- **Have any of you ever had an operation? What was this like?**
- **What do patients do before, during, and after surgery?**
- **If you had surgery, who would you want with you in the recovery area?**

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Video Guide 8:
Are Therapies Covered?

This vignette explains how insurance companies deal with the coverage of certain therapies. A distinction is made between medically related and educationally related therapies. Important tips for improving coverage are discussed. The mother of a young woman who is recovering from hip surgery talks about her experiences with her insurance company.

1. **"Medically-Related Therapies"** These types of therapies are time-limited treatments. They are typically prescribed by a physician in response to an injury or surgical procedure. Medically-related therapies have specific goals. For example Katherine in the video had recently undergone hip surgery. Her physician prescribed therapy explicitly for pain management. Katherine's therapy was clearly a medically related treatment.

2. **"Education-Related Therapy"**
   This type of therapy is on-going. For example, it may happen several times per week for several years. The goals of this type of therapy are long term. Examples are speech therapy to develop a communication program and physical therapy that is focused on therapeutic ambulation. These therapies have functional goals that are not strictly medical. Rather, the focus is on habilitation and education. These therapies are extremely important for improving the quality of a person's life. Education-related therapies are typically provided for children in the elementary school setting. However as children grow up and enter middle or high schools, therapies are often cut from their Individualized Education Plan (IEP). Schools state that if therapy goals have not been met in the adolescent years, or if limited progress is noted, that the focus of the IEP should shift from habilitation to accommodation. This rationale is not supported by many groups who advocate for youths who have developmental disabilities, but the law that oversees the education process supports decisions made by school districts. Many children could and would benefit from on-going therapies in their middle-school and high-school years.

Questions for Group Discussion

- **What are examples of medically-related therapies?**
- **What are examples of education-related therapies?**
- **What are the goals of therapies that you receive?**

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Video Guide 9: Beware of Timetables

This vignette features a grandmother who is the legal guardian of her granddaughter who has cerebral palsy. She is having a conversation with her lawyer about coverage for her granddaughter once the child turns 18 years-old.

1. **"She'll be covered forever, right?"**
   Insurance companies can change their policies on a yearly basis. Consumers need to pay attention to the changes in their policies and make sure that the coverage from one year to the next is affordable and adequate for their family. It is not always easy to understand insurance policies and coverage. This is an area where families may need help determining which policy is the best one for them.

2. **"Get it in writing!"**
   Please Note: the information in this video is outdated. The Young Adults and Affordable Care Act, effective March 3, 2010 allows young adults to stay on parents insurance until age 26.

3. **"Become more independent."**
   This peer counselor points out that speaking up is skill that is essential for becoming more independent. Discuss what it means to "speak up."

Questions for Group Discussion

- **At what age are most children cut off from their parent's health insurance policy?**
- **What is the exception to this rule?**
- **Why is it important for a family to contact their insurance carrier before one turns 18?**

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Video Guide 10: Insurance Options Before Age 18

This vignette features a grandmother who is the legal guardian of her granddaughter who has cerebral palsy. She is having a conversation with her lawyer about coverage for her granddaughter. The lawyer explains the various insurance options available to children with disabilities in New York State.

1. **"COBRA"**
   COBRA is a law that guarantees the right to purchase insurance coverage at group rates for 18 months, or sometimes longer, if a parent loses employment based insurance coverage because of a change in job or due to job loss.

2. **"Child Health Plus"**
   Child Health Plus is available to families who do not qualify for Medicaid insurance. It is available to children in New York State until age 19 years.

3. **"Medicaid and SSI"**
   The attorney points out that Medicaid is available to families who have low income. Persons with disabilities who qualify for SSI from the federal government automatically qualify for Medicaid in New York State. It is important to submit paperwork for SSI determination or re-determination when a child turns 18 years old.

Questions for Group Discussion

- **What does the COBRA law say?**
- **What is Child Health Plus?**
- **At what age should persons with disabilities submit paperwork for SSI determination?**

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Video Guide 11:
Decision Making w/Circle of Support

A circle of support is presented as an alternative to legal guardianship. Individuals with developmental disabilities talk about their circle of support. Examples are given to show how a circle of support can help an individual with making decisions, problem-solving, and planning for the future.

1. "What is a circle of support?"

- **People who know us best**
- **Informal (not legal)**
- **Meet together as a group**

2. "How can a circle of support help the individual?"

- **Planning**
- **Problem Solving**
- **Making decisions**

Questions for Group Discussion

- **What is a circle of support?**
- **How can a circle of support help with decision making?**
- **Do you have a circle of support?**

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Video Guide 12: Alternatives to Guardianship

Several alternatives to guardianship are presented in this vignette. Young adults with developmental disabilities discuss the arrangements that they have made for themselves. Conservatorship, Power of attorney, Representative payee, and Independent decision making are discussed.

1. **"Conservatorship"**
   Conservatorship is a legal designation of a person to be responsible for the assets and finances of another person who is deemed fully or partially incapable of managing these functions. People sometimes only need a conservator for a short time, for example, when they are in a hospital. A conservator must complete an annual accounting of the financial records.

2. **"Power of attorney"**
   This is a voluntary, private agreement by which a competent individual gives another person (known as an agent) power to handle financial matters for the individual. The agreement should be signed, witnessed by at least two individuals, and notarized. To establish a power of attorney you do not need judicial (court) approval. There is also no annual financial accountability. A power of attorney cannot manage social security funds. A representative payee must be established for this purpose.

3. **"Representative payee"**
   This is a person who is designated by the person with a disability to receive a payment of a basic benefit such as an SSI or SSDI check and manage that money for him or her.

4. **"Independent decision making"**
   Parents can be threatened by the prospect of their son or daughter making independent decisions or by the thought of having someone take advantage of them. Learning to let go, taking risks, and learning to trust is a process that needs to be nurtured and takes time. Everyone plays a role in advocating for the least restrictive alternative to guardianship, when appropriate.

Questions for Group Discussion

- **What are the alternatives to guardianship?**
- **Why is it important to establish some sort of oversight for financial matters?**
- **What kinds of financial decisions do you make yourself?**

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Video Guide 13:
Guardianship: A Parent's Perspepctive

It is different for every parent, but the importance of establishing guardianship for children who are unable to make their own decisions is one of the most important decisions a parent can make for a child.

"Tips from a parent"

- **Guardianship papers are as important as an insurance card.**
- **Carry them in your wallet at all times.**
- **Research the topic before starting the proceedings.**
- **Start early, when a son or daughter is about 16 years old.**
- **It takes a long time to complete the paperwork.**
- **All the paperwork must be notarized.**
- **It is not necessary to hire a lawyer.**
- **Local agencies sponsor workshops that help a parent get through the process.**
- **The court fees are not expensive.**
- **Guardianship guarantees advocacy.**

Questions for Group Discussion

- **Have you ever discussed guardianship?**
- **At what age should parents start looking into guardianship?**
- **What are your thoughts about guardianship?**

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Video Guide 14:
17-A Surrogate Court Procedure Act

In this vignette an attorney explains the distinctions between custodial guardianship that is established in Family Court and legal guardianship under the 17-A Surrogate Court Procedure Act.

1. "Custodial guardianship"

The attorney in this vignette explains the difference between custodial guardianship that is established in Family Court, and legal guardianship under 17-A Surrogate Court Procedure Act. Custodial guardianship only applies to children under the age of 18, whereas legal guardianship under 17-A is lifelong. Surrogate court guardianship is typically established at age 18.

2. "Legal guardianship under 17-A Surrogate Court Procedure Act"

Surrogate Court is where one goes to establish legal guardianship for persons older than 18 years who have a physical or mental condition that prevent them from taking care of their own basic needs; who are in danger of substantial harm; and who have no person already legally authorized to assume responsibility for them.

3. "Take home points about 17-A Guardianship . . ."

Lifelong, but can be terminated by either the guardian or the individual by procedures outlined under the Surrogate Court Procedure Act.

- **Allows parent to name a stand-by guardian and an alternate stand-by guardian.**
- **Apply for this guardianship at age 18.**

Questions for Group Discussion

- **What is the difference between custodial guardianship and legal guardianship?**
- **At what age should one apply for legal guardianship under 17-A?**
- **Why do you think so many people put off establishing guardianship?**

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Video Guide 15:
Using a Dynamic Display Device

In this vignette an adolescent with cerebral palsy and her aide demonstrate the pros and cons of using a dynamic display communication device.

1. **"What is a dynamic display communication device?"**
   Brooke and Jenna explain that the dynamic display communication device (Dynavox) is a portable touch screen computer that allows Brooke to ask questions and make statements. Brooke can select words, symbols or letters from cells that Brooke and Jenna have created on the computer. Speech is generated when Brooke makes a selection. Direct touch, switches, or eye scanning is used to make selections.

2. **"Brooke likes to talk on the phone"**
   The Dynavox allows Brooke to talk with friends who call, or to make a phone call herself. The Dynavox allows Brooke to communicate with statements and questions rather than simply responding yes or no to statements and questions that are presented to her. Jenna explains that yes/no communication works well for certain situations. Jenna recalls that it took a little bit of time to get used to having a conversation using yes/no communication. Brooke's speech therapist comments on Brooke's excellent auditory memory.

Questions for Group Discussion

- **What are some of the pros and cons of yes/no communication?**
- **What are some of the pros and cons of using a dynamic display communication device?**
- **Have you ever seen or used a dynamic display communication device?**

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Video Guide 16:
Role of Aides at Appointments

In this vignette a young woman with cerebral palsy discusses a frustrating experience she had at her doctor's office. The doctor spoke to her aide, and treated Nikki as if she were non-verbal. Together the young woman and her service coordinator develop strategies for avoiding this sort of situation in the future. Communication etiquette is discussed.

1. **"He treated me as if I were non-verbal and that doesn't work for me"**
   Nikki explains to her service coordinator that she was frustrated by an encounter with a doctor who spoke to her aide rather than to her, even though she was the patient. Nikki's spasticity affected her ability to communicate by speech when she became angry during the medical visit. Nikki relays this experience to her service coordinator.

2. **"Speaking up is just another skill . . . "**
   The service coordinator points out that speaking up is a skill that can be developed. She suggests role play. Nikki practices "speaking up" when a co-worker she meets in the hallway begins a conversation with her aide without addressing Nikki directly. Thanks to role play and practice, Nikki is now able to speak up. The co-worker recognizes the importance of communication etiquette when conversing with individuals who have aides. Doctors and nurses can improve communication with adolescents who have developmental disabilities by talking directly to their patients, and by expecting their active participation at every health care visit. All too often physicians and nurses talk to parents or aides, rather than directly with the young adult patient. This sends a message that it is "OK" to be passive. Nikki's experience demonstrates that this is not OK!

Questions for Group Discussion

- **Why did the doctor assume that Nikki was non-verbal?**
- **What can Nikki do to teach "communication etiquette" to her doctor?**
- **Did a doctor ever assume that you were non-verbal?**

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Video Guide 17: Acknowledge Circle of Support

The take home message for this vignette is that doctors and nurses can improve communication at medical visits by understanding the role of family caregivers and other members of an individual's circle of support. Friends and family who come to appointments play a supportive role. It is the individual who takes the lead in discussions about his/her own health.

1. **"Amy and her mother come to a medical appointment to discuss . . ."**
   The doctor in this vignette directs his questions to Amy. He greets both Amy and her mother, but the appointment clearly is focused on Amy, because she is the patient. Amy answers the doctor's questions, and then turns to her mother who provides additional information.

2. **"Amy's day-hab cooking class . . . "**
   The vignette demonstrates that a doctor's recommendations to a patient who has a developmental disability are implemented with the help of the circle of support and/or formal habilitation services. Effective doctor-patient communication explicitly recognizes these supports.

Questions for Group Discussion

- **What is a circle of support?**
- **Why is it important to have a circle of support?**
- **Would you want someone from your circle of support with you when you go the doctor?**

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Video Guide 18: GLADD

This vignette introduces the GLADD mnemonic (Give, Listen, Ask, Decide, Do) as a technique for speaking up at the doctor's office. The GLADD mnemonic was developed by the Institute for Child Health Policy in Florida. Adolescents discuss how they learned to speak up at the doctor's office.

1. **"G-L-A-D-D"**
   The mnemonic stands for:
   - **G**ive information
   - **L**isten to what the doctor or nurse has to say
   - **A**sk questions
   - **D**ecide on a plan
   - **D**o your part to follow through on the plan

2. **"Getting started . . . "**
   An adolescent explains that she does research about her health condition before going to a doctor's visit. This way she is prepared to ask questions. She suggests practicing what you want to say as another strategy.

3. **"Parents can help by stepping back . . . "**
   An adolescent relates that doctors tended to ignore her and spoke to her mother instead. Her mother told the doctor to "ask the patient". The adolescent comments that her mother helped her to speak up for herself by stepping back, and letting her do the talking.

Questions for Group Discussion

- **What does GLADD stand for?**
- **Why is it important to give information?**
- **Why is it important to decide on a plan?**

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Video Guide 19: Speak Up!

In this vignette an adolescent meets with a peer counselor at a regional Independent Living Center. She relates that she rarely speaks up at the doctor's office. Her habit is to stay quiet until someone asks her a question. The peer counselor suggests that she practice speaking up.

1. **"Her habit is to be quiet . . . "**
   Many adolescents are anxious or shy at the doctor's office. However, as adolescents enter the adult health care system, it is essential that they know how to communicate effectively with their health care team. Ask participants whether they have ever initiated a discussion with their health care providers.

2. **"Speaking up is just another skill . . . "**
   The peer counselor points out that speaking up is a skill that can be developed. He suggests role play, and practice. Doctors and nurses can encourage skill development by talking directly to adolescent and young adult patients, and expecting their active participation at every health care visit. All too often physicians and nurses talk to parents or aides, rather than directly with the young adult patient (see "Role of Aides at Medical Appointments"). This sends a message that it is "OK" to be passive, further exacerbating the situation.

3. **"Become more independent."**
   This peer counselor points out that speaking up is skill that is essential for becoming more independent. Discuss what it means to "speak up."

Questions for Group Discussion

- **Why is it important to speak up at the doctor's office?**
- **How can you learn to speak up if you are shy?**
- **Do you ever speak up at the doctor's office?**

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Video Guide 20: Ask Me 3

This vignette presents a strategy that patients can use to better understand the health care recommendations that are made by doctors and nurses. A peer counselor at an Independent Living Center explains that 3 simple questions should be answered at every health care encounter. He explains that this approach will actively involve the adolescent with her own health care.

1. **"Ask Me 3"**

   The three questions every patient should ask at every health care encounter are:

   1. **What is my main problem?**
   2. **What do I need to do?**
   3. **Why is it important for me to do this?**

Questions for Group Discussion

- **What are the three questions for "Ask Me 3"?**
- **Why are these three questions important for staying healthy?**
- **Do you ever ask these questions when you are at the doctor's office?**

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Video Guide 21: The Pre-employment Physical

In this vignette an employment counselor reviews what health information is needed in order to match clients with the right job. She explains that a medical report is often requested, and that this is used to determine whether there are physical limitations, or issues such as memory deficits, poor hygiene, or limited social skills that should be addressed proactively.

1. "Accurate and relevant medical information . . . "

The employment counselor lists the information that she looks for in medical reports:

- **Physical issues such as fatigue, problems with lifting, or sensory impairments**
- **Memory deficits**
- **Learning disability**
- **Hygiene**
- **Social skills**

2. "The pre-employment physical . . . "

The physician has an open and honest discussion with a young adult patient about her disability. He helps her to identify areas to focus on proactively, such as hygiene and social skills, while she is still in high school. The video underscores the important role that health care providers can play in preparing adolescents with developmental disabilities for long term employment.

Questions for Group Discussion

- ▶ **What do employment and job counselors do?**
- ▶ **What health information does an employment counselor need to know?**
- ▶ **How can health care providers help employment counselors?**

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Video Guide 22: Keeping a Health Diary

This vignette introduces the concept of self monitoring of symptoms with a health diary. Several formats are presented, including a calendar and a blog. The vignette illustrates how a health diary can be used to keep track of symptoms, to monitor whether a new medication is effective, and to determine whether there are side effects when one starts a new medication.

1. **"Keeping track of symptoms . . . "**
   An example is provided of a young man with spina bifida who keeps track of headache symptoms with the help of his sister. The diary helps his health care team to diagnose and treat this condition.

2. **"Monitor medication side effects . . . "**
   The vignette points out that a calendar or blog can be used as a health diary to monitor for medication side effects and to determine whether a new medication is effective.

3. **"A health diary helps you to understand your disability . . . "**
   A health diary is a great way to become more aware of one's own health and to become more actively involved with one's own health care.

Questions for Group Discussion

- **What is a health diary?**
- **How can a calendar be used as a health diary?**
- **Do you keep a health diary?**

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Video Guide 23: Brown-bag Medications

This vignette illustrates the importance of bringing all medications to the doctor's office in a brown bag or some other container. It is an especially effective practice when a person has more than one medical provider.

1. **"Heather has made it a habit to bring all her medications to all doctor visits . . .**
   It is important to bring all prescriptions to every appointment. This is a good way to make sure that all medical providers know about all of the medications that have been prescribed. The doctors and nurses can also make sure that there are no unsafe drug interactions. They can write refills for prescriptions that are running low. Brown bagging medications at every doctor's visit is also a good reminder to review why medications are being taken.

2. **"Brown bagging medications is a great way to partner with health care providers . . . "**
   Self determination is important, but some people are unable to competently manage their medication administration. This cannot be overlooked. A person who is unable to effectively manage his or her own medications should consider establishing a health guardian or health care proxy. Visiting nurses can sometimes be employed to assist with medication administration.

Questions for Group Discussion

- **Why is it important to bring all medications to all doctor's visits?**
- **Do you talk with your doctor about why you take your medications, and side effects?**
- **Do you bring your prescriptions bottles with you to doctor's visits?**

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Video Guide 24: My Medschedule.com

This vignette introduces a website that can be used to create a medication schedule with pictures of pills. A young woman with cerebral palsy demonstrates how to use the website to create a personal medication chart. The website also offers several reminder systems to assure that an individual takes his/her medication on time and is aware of how much to take each day.

1. **"Creating an account at mymedschedule.com . . . "**
   Mymedschedule.com is free. Users of the site need to register to use the site. All information is protected by password and SSL encryption. First a user name must be established. Second, a password must be created. Make sure to write down the user name and password.

2. **"There are four easy steps to follow in creating a medication chart . . . "**

   Step 1: Select a medication from the pull-down menu.

   Step 2: Indicate how many pills you need to take and when to take your medication.

   Step 3: Check that the picture and the time and date to take the medications is correct.

   Step 4: Print the schedule.

3. **"Taking an active role in your own health care . . . "**
   Mymedschedule.com is a great learning tool. It can help a person to become more organized and well prepared. Reading is a necessary skill to use this website. Familiarity with computers and the Internet are also pre-requisites. Supporters can help to create the chart for non-readers or for individuals who do not have computer skills or ready Internet access. Health care providers should review the chart to assure accuracy.

Questions for Group Discussion

- **What is Mymedschedule.com?**
- **Why is it important to keep a medication chart?**
- **How do you keep track of your medications?**

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Video Guide 25: Prescription Labels & Organizers

In this vignette an adolescent with cerebral palsy demonstrates how to call in a prescription refill. The phone call begins with her saying that she is calling in a prescription refill. She then gives her prescription number, explains that she will pick up the prescription, and says thank you. The use of a pill organizer is also discussed.

1. **"Take a look at the label . . . "**
   There is a great deal of useful information on a prescription label. The video begins with an animation that reviews all the components. Ask participants to discuss why this information is useful.

2. **"When you call the pharmacist . . . "**
   Many people are confused by voice mail prompts. Explain that most voice mail recordings will include a prompt for speaking directly with the pharmacist. Simply staying on the line is another strategy for speaking directly with the pharmacist. Discuss why it is important to say why you are calling in a clear and concise manner.

3. **"You might be asked . . . "**
   Make sure that participants understand that the pharmacist may ask the caller several questions. For example, the pharmacist may ask when or how the prescription will be picked up.

4. **"Medication organizers can be very helpful . . . "**
   This part of the vignette demonstrates the use of a pill organizer. A pill organizer is best filled with supervision, to assure accuracy. The original bottle and prescription label should always be retained.

Questions for Group Discussion

- **What do you need to have ready before calling in a prescription refill?**
- **What information does the pharmacist need when you call for a refill?**
- **Have you ever called in a prescription refill?**

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Video Guide 26: Keeping a Health Summary

This vignette addresses the importance of maintaining personal health care records. Topics covered include: getting started; developing a time line; contact information; a list of health care providers; tools available for families to use; and transitioning from pediatric providers to adult providers. The vignette features a mother's experiences with her 24 year-old daughter.

1. **"Let's get started . . ."**
   How we keep records varies from family to family. The mother featured in the vignette has a black appointment book with an assortment of documents, clippings, and information she has collected about her daughter's medical care. She brings it to every medical appointment that she attends. She uses it as a personal reference, not something she shares with providers. Collecting documents and information is the first step towards keeping a health summary.

2. **"Getting organized . . ."**
   Organizing the files to make them accessible and meaningful is the next step. The mother in this vignette explains how the health care notebook from Parent to Parent of New York State can help youths and families to organize health information. She also explains that it is useful to keep a time line of important surgeries or events.

3. **"Sharing information . . ."**
   Organizing and prioritizing information to share with medical providers and human service agencies is important. Too much information can be as bad as not enough information. Pediatricians can help to prioritize information during the transition to adult health care.

Questions for Group Discussion

- **Why is it important to keep a health summary?**
- **What are key steps involved with developing a health summary?**
- **Do you have a medical summary or health record that you keep for yourself?**

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Video Guide 27: The Transition Information Form

The Transition Information Form was designed to provide accurate and up-to-date information that is important and useful in case of a medical emergency or for purposes of transitioning from one provider to another. The vignette features a mother's experiences with using the form with a new service provider who will be working with her adult daughter.

1. **"The Transition Information Form can be used for a variety of purposes . . ."**
   It can be used as a planner during routine health care visits. It can be used as a medical summary during emergencies. It can be used to combine and share information among family caregivers, medical providers, and habilitation service providers. It can be used to stay organized during any transition process.

2. **"Columns for Pediatric and Adult Health Care Providers . . ."**
   The Transition Information Form includes a provider list with a column for pediatric care providers, and a column for corresponding adult health care providers. This is a good way to stay organized when transitioning to the adult health care system.

3. **"Baseline Information . . ."**
   This section of the Transition Information Form provides information about an individual's normal baseline physical exam. Discuss what might be included in this section, e.g. height and weight. Discuss why this might be important when transitioning to a new health care provider.

4. **"Emergency Management Information and Health Maintenance Information . . ."**
   Discuss the difference between emergency health care and health care that is focused on wellness and prevention. What sort of information is included in these two sections of the Transition Information Form?

Questions for Group Discussion

- **Why is it important to have a Transition Information Form?**
- **Give examples of situations where a Transition Information Form might be useful.**
- **Do you have a medical summary or health record that you keep for yourself?**

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Video Guide 28: Meeting with a Service Coordinator

This vignette illustrates how the relationship of a service coordinator to the individual with a disability needs to be both comfortable and productive. The service coordinator plays a critical role in identifying strengths and needs, providing supports, and helping to set up goals for success and self advocacy.

1. **"How often does one meet with a service coordinator?"**
   A service coordinator meets with the individual who has a developmental disability on a monthly basis.

2. **"Where does one meet with a service coordinator?"**
   Meetings can take place at the person's home, the service coordinator's office, or at a community location. It should be at a location most convenient to the person with a disability and not the other way around.

3. **"What does the service coordinator do?"**
   A service coordinator is a very important person in the life of a person with a disability. Service coordinators need to be open minded and good listeners. They need to assist with setting up life goals by assessing the wants, strengths, and needs of the person with a disability. Service coordinators help people develop a plan to prioritize and accomplish their goals. They are also responsible for assuring the person lives in an adequate and safe environment. Of great importance is the role the service coordinator plays in advocacy. The service coordinator needs to be a steady and strong advocate for the wants and needs of the person with a disability. A service coordinator addresses all the major areas of life: psychological, social, vocational, family, financial, and developmental. This topic is revisited in vignette 29 (Finding an Effective Service Coordinator).

Questions for Group Discussion

- **What can a service coordinator do for you?**
- **How often should a service coordinator meet with you?**
- **Do you have a service coordinator?**

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Video Guide 29:
Finding Effective Service Coordinator

This vignette describes the qualifications of a service coordinator, and the types of services he/she can provide or broker. The term "effective" is key in this vignette. Not all service coordinators are equally effective. Examples of effective service coordination are provided. A mother, whose daughter has been involved in the human service delivery system, shares her insights.

1. **"Plan for a smooth transition..."**
   Some needs are predictable developmental issues, but others are not. Life also has its unpredictable moments. An effective service coordinator can make a big difference in how all transitions are handled. A service coordinator should be able to anticipate certain changes and in doing so, prepare ahead of time. On the other hand a service coordinator should also be aware of emergency services, such as respite providers, and be able to access them as well. Services are not always available when we need them. People who plan ahead stand a much better chance of getting what they want or need when they want or need it. Some services are so individualized that they need to be created. It takes time to create services.

2. **"An effective service coordinator gets things done..."**
   Not all service coordinators have the same knowledge base, level of efficiency, ambition, or work ethic. It's important to choose a coordinator who works promptly and efficiently. One month can be a very long time if one really needs or wants something. Don't let too much time go by without getting what is needed. Contact the service coordinator's supervisor if necessary.

3. **"A service coordinator is an advocate..."**
   An effective service coordinator needs to be aggressive and assertive at times. Advocacy is one of the most important roles of the service coordinator. Discuss what this means.

Questions for Group Discussion

- **What qualifications must a service coordinator have?**
- **Give examples of effective service coordination.**
- **Is your service coordinator effective?**

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Video Guide 30: Developing a Safety Plan

In this vignette a young adult with cerebral palsy discusses her safety plan with her service coordinator. Their conversation provides an overview for what service coordinators should do to address safety. Examples include notification of public service providers, and home modifications.

1. **"Alert public safety providers "**
   It is the responsibility of the service coordinator to assure that the home environment is both adequate and safe. Getting out of a house in an emergency is not just a physical issue. Fear and anxiety are as important to discuss as the physical limitations. The safety plan may include notification of the local fire department and police department about particular safety issues such as mobility impairment, need for emergency electrical services, or wandering.

2. **"Environmental modifications"**
   Kitchens and bathrooms need to be easily usable to be safe. People in wheelchairs are better able to use a kitchen if counters and handles are lowered to their sitting height. Handles can easily be added to areas where a person needs to get in and out of their wheelchair, i.e. bathtubs or toilets. Shower stools, electric lifts, night lights, water-temperature-equalizers, timers on appliances, and clap-on lights are also important to consider. There are people at the local DSO (OMRDD- Developmental Services Office) who are trained in home modifications for safety and independence. A service coordinator can arrange for a physical or occupational therapist to do an in-home assessment.

Questions for Group Discussion

- **Why would you need a safety plan?**
- **Who are the people or services that should be notified about your disability?**
- **Why are home modifications important?**

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Video Guide 31: Creating An Individual Service Plan

This vignette explains the concept of an individualized service plan and the role that self determination plays in developing this plan. The vignette summarizes how the two concepts are intimately intertwined. A young woman with a disability who is a consumer of services is interviewed. Her experiences and feelings about self-determination are shared.

1. **"Your service coordinator is there for you . . ."**
   The narrator explains: the role of this person is to listen to your goals and to help you reach them.

2. **"Self determination . . ."**
   Self Determination is different from the traditional service coordination. It takes into account the individual differences in people's wants and needs and allows for greater flexibility in the ways in which a service can be provided. It is the job of the person with a disability to determine the goals and it is the job of the service coordinator to help the person reach them.

3. **"The Individualized Service Plan"**
   The individualized service plan is a blueprint of the goals and services needed to achieve those goals. The individualized service plan summarizes the strengths and goals of the person as well as what help the person wants and needs to achieve his/her stated goals. The individualized service plan helps people to prioritize their goals by discussing the concept of valued outcomes.

Questions for Group Discussion

- **What does ISP stand for?**
- **What is self determination?**
- **What are your valued outcomes?**

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Video Guide 32:
My Health, Choice, Responsibility

This vignette introduces a training program that was developed by the Westchester Institute for Human Development in collaboration with the Self Advocacy Association of NYS. The training program includes a free manual that can be used by groups to help individuals who have developmental disabilities to develop healthy lifestyles.

1. **The seminar consists of seven sessions:**
   - **Developing a health plan**
   - **Self Advocacy at the doctor's office**
   - **Physical activity**
   - **Nutrition**
   - **Safety and cleanliness at home**
   - **Hygiene**
   - **Emotional health**

2. **"My responsibility . . . "**
   Individual responsibility is a common theme throughout the curriculum. For each unit, the participants are asked to consider the following: (a) Can I do this on my own? (b) Do I need help with this? (c) What help is needed? (d) Who can provide the support to me?

Questions for Group Discussion

- **Why do you think the title "My Health, My Choice, My Responsibility" was used?**
- **Name the seven sessions in the "My Health, My Choice, My Responsibility" curriculum**
- **Which topic is most important to you?**

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Video Guide 33: Self Determination and Health

In this vignette four key elements of self determination are highlighted: (a) Choosing a goal, (b) Expressing that goal, (c) Identifying the steps that are needed to accomplish the goal, and (d) Follow-up to monitor progress. Two young adults demonstrate how they set health goals with the help of their service coordinators.

1. **"Self determination is . . . "**
   The vignette begins with an explanation of the four key elements of self determination: (a) Choosing a goal, (b) Expressing that goal, (c) Identifying the steps that are needed to accomplish that goal, and (d) Follow-up to monitor progress.

2. **"My service coordinator lets me steer the ship"**
   A young man with cerebral palsy explains how his service coordinator promotes self determination.

3. **"Here is an example . . . "**
   A young woman and her aide have set weight loss as a health goal. The aide provides a food pyramid for making food choices. The young woman expresses her choices by making a grocery list. Together they monitor progress by tracking her weight.

Questions for Group Discussion

- **What is self determination?**
- **How can your service coordinator help you to set health goals?**
- **What are some health goals that you would like to set for yourself?**

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Video Guide 34:
How to Use the Transition Checklist

This vignette presents a list of ten skills that promote independence with managing one's own health care. The transition checklist is designed to help a person assess his or her current skill level, to set goals for skill development, and to keep track of progress. Skills are loosely grouped into activities that occur before during and after medical appointments.

1. **"Skills before going to the appointment"**
   Scheduling an Appointment and ***Getting Health Insurance*** are important to learn before going to an appointment.

2. **"Skills that are used at the appointment"**
   Deciding About Guardianship and ***Speaking Up at the Doctor's Office*** are important to understand while an individual is at the doctor's appointment.

3. **"Skills to discuss with your doctor"**
   Understanding My Disability, Managing Medications and ***Keeping a Health Care Summary*** are important issues to negotiate with one's health care provider.

4. **"Skills to develop after the appointment"**
   Looking Into Service Coordination, Setting Health Care Goals and ***Finding Community Resources*** are skills that can be learned after a visit that may help a person build a relationship or partnership with a service coordinator and/or circle of support.

5. **"Review the transition checklist at every health care visit..."**
   Skill development does not need to occur in a particular order. It is useful to review the checklist at every health care visit. Skills are developed over time, and with practice.

Questions for Group Discussion

- **Can you name the 10 skills on the transition checklist?**
- **Why is it important to master the skills on the transition checklist?**
- **Which skills are important to you?**

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Video Guide 35: Summer Camp

This vignette addresses the topic of attending a sleep-over summer camp. The advantages of such an experience for the child are juxtaposed with the emotional ambivalence of the parent. A camp counselor gives her perspective. A mother discloses her fears.

1. **So tell me exactly what happened . . . "**
   Parents of adolescents who have a disability often recognize the need for their child to attend a sleep-over summer camp, but fear their child's specific needs will not be addressed adequately. Parents need reassurance, which may come in the form of detailed accounts of their child's experience.

2. **"Because I trusted you . . . "**
   Parents are much more likely to feel comfortable if their child can go to a camp where at least one adult knows their child well and can meet his or her needs. Every child, disabled or not, needs to discover his or her inner strengths and resources. Often the parent of a child with a disability struggles with balancing caregiving for the child with letting go of the child. Parents need to be gently supported to take these risks. To them, the risk is not just about the child. It is also about their responsibility to their child. Support can come in many ways. Information is a great source of support. Knowing and trusting a caregiver is also a support. Allowing a parent to be anxious about the experience without judgment is a support. Holding the hand of an anxious parent is a support. Reassurance is a support. Finding another parent of a child with a disability who is willing to share his or her experiences about the same issue is a support.

Questions for Group Discussion

- **Describe the people in this video. What are they feeling?**
- **Why is sleep-over summer camp an important experience?**
- **Have you ever been to a sleep-over summer camp?**

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Video Guide 36: VESID and Job Placement

This vignette gives an overview of the NYS Office of Vocational and Educational Services for Individuals with Disabilities (VESID). A list of the services provided by VESID is reviewed. A young man with a disability and his employment counselor are interviewed.

1. **"What is VESID?"**
   New York State has an Office of Vocational and Educational Services for Individuals with Disabilities (VESID). This office has been set up to assist people with a disability who are graduating from high school to transition to a post-secondary placement. The placement can be an employment opportunity or an educational opportunity that will eventually result in employment. The vocational services VESID provides include the following: Vocational assessment and counseling, Job training and placement, Job follow-up, Transportation training, Drivers assessment and education.

2. **"VESID counselors can help with . . ."**
   Examples of the skills and assistance that VESID counselors provide include: Interview skills for getting a job; Identifying what one needs to do before going on the interview; Practicing what you might say while on the interview; Identifying and practicing what you do following the interview; Helping to identify what restrictions you may have, or help you may need from an employer.

3. **"Practice answering the following questions:"**
   Why do you want this job? What skills do you have that make you a good choice? Do you know what the job entails? Can you tell me about your previous experiences with work? Are you good with people? How would you describe your work habits? What would your previous supervisor say about you? Why should I hire you for this position?

Questions for Group Discussion

- **What is the goal of VESID?**
- **What are some questions you might be asked at a job interview?**
- **What does a job coach do?**

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Video Guide 37: Circle of Support

This vignette introduces the idea of establishing a circle of support. Whom to pick for a circle of support is discussed, as are the legal implications surrounding this group. Individuals with developmental disabilities are interviewed, and the types of supports they have received from their own circle are discussed.

1. **"Everyone needs help . . . "**
   The need for social support is not just for people who have a disability. Everyone needs support at various times throughout his or her life. Asking for help is not a sign of weakness. It is a sign of strength and good judgment. Common examples of help we receive through our life include borrowing money to purchase a car or a home, calling a friend or a parent to care for a young child or an ailing relative, asking a friend or family member for a ride to school or work, calling a friend on the phone when we are upset and need to talk, or asking our boss for a day off to attend some other event. Have participants list all the ways he or she can think of that people help one another.

2. **"The people who know us best . . . "**
   People with good social support systems are happier and healthier. Feelings of attachment and belonging have a tendency to give rise to feelings of happiness and self-worth. Social support is also associated with the ability to cope. People who have good social support systems are less prone to depression. Support is not about telling someone what they need. It is more about exploring the topic through discussion, observation, and asking the right questions.

3. **"Meet with your group . . . "**
   There are many things to discuss with your circle of support. One example of the type of advice members of a circle of support may give is evaluating how safe their current living arrangement is. The circle of support may also give people advice and physical support that can assist them to move to an even less restrictive environment such as their own apartment.

Questions for Group Discussion

- **What is a circle of support?**
- **Who are some of the people who know you best?**
- **What are examples of decisions that a circle of support can help you with?**

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Video Guide 38:
OPWDD (formerly OMRDD) Part One

The video begins with an overview of the OPWDD/DDSO system. Next, an adolescent with spina bifida and her step-mother meet with their service coordinator. The service coordinator reviews the services and supports that are available via the OPWDD. Topics include service coordination, the individualized service plan, and day habilitation.

1. **"OPWDD/DDSO system . . ."**
   The narrator explains that OMRDD stands for Office of Mental Retardation and Developmental Disabilities. This is a statewide system that is organized into 13 regional Developmental Disability Services Offices. *Please note that the OMRDD was renamed the Office for Persons with Developmental Disabilities (OPWDD) in 2010.*

2. **"When I meet Desireh . . . "**
   The service coordinator explains that she meets with Desireh and her family on a regular basis. Her role is to help them access community supports and services. She explains that the Individualized Service Plan was developed for Desireh with input from core people in Desireh's life, including family and advocates.

3. **"Day habilitation . . . "**
   The service coordinator explains that day habilitation programs help Desireh to build new skills and to become integrated in the community.

Questions for Group Discussion

- **What does OPWDD stand for?**
- **What is day habilitation?**
- **In what ways does the OPWDD help you?**

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Video Guide 39:
OPWDD (formerly OMRDD) Part Two

This video is a continuation of Video #38. It provides additional information about services and supports that are available via the OPWDD. Topics include respite and environmental modifications.

1. **"Everything you can think of . . . "**
   The service coordinator explains that she accesses a wide variety of services for individuals who have developmental disabilities: residential living situations, new doctors, guardianship, advocates, educational services, to name a few.

2. **"Respite..."**
   Desireh attends a respite program that gives her parents a break and that has allowed her to make several new friends.

3. **"Environmental modifications: You should not throw in the towel too easily . . . "**
   The service coordinator and Desireh's stepmother discuss the steps involved with getting bathroom modifications for Desireh's new home. The stepmother explains that the process is complicated and can take a long time, but that it is important to be persistent.

Questions for Group Discussion

- **Name the types of services a coordinator can identify and access for an individual.**
- **What is respite?**
- **What are environmental modifications? Why are these important?**

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Video Guide 40: Independent Living Centers

An adolescent and her mother meet with a peer counselor at their regional Independent Living Center. The peer counselor discusses the array of services offered at Independent Living Centers. Topics include: peer counseling, driving assessments, home modifications, independent living skills, and advocacy.

1. **"Independent Living Centers are run by and for people with disabilities . . . "**
   The counselor explains that Independent Living Centers are a national network of community based centers that employ at least 50% individuals with disabilities. He explains that Independent Living Centers are non-residential, rather community based...

2. **"Can you tell me about peer counseling . . . "**
   At least 50% of employees at Independent Living Centers are people with disabilities. Peer counseling based on life experience is readily available.

3. **"Driving"**
   Experts at Independent Living Centers can help determine what type of hand controls are needed, and whether to get a van or car.

4. **"Home modifications"**
   The peer counselor explains that most Independent Living Center have resource libraries with information about how to make a home accessible, more "user friendly".

Questions for Group Discussion

- **What is an Independent Living Center?**
- **List the services that one typically finds at an Independent Living Center.**
- **How can you locate an Independent Living Center?**

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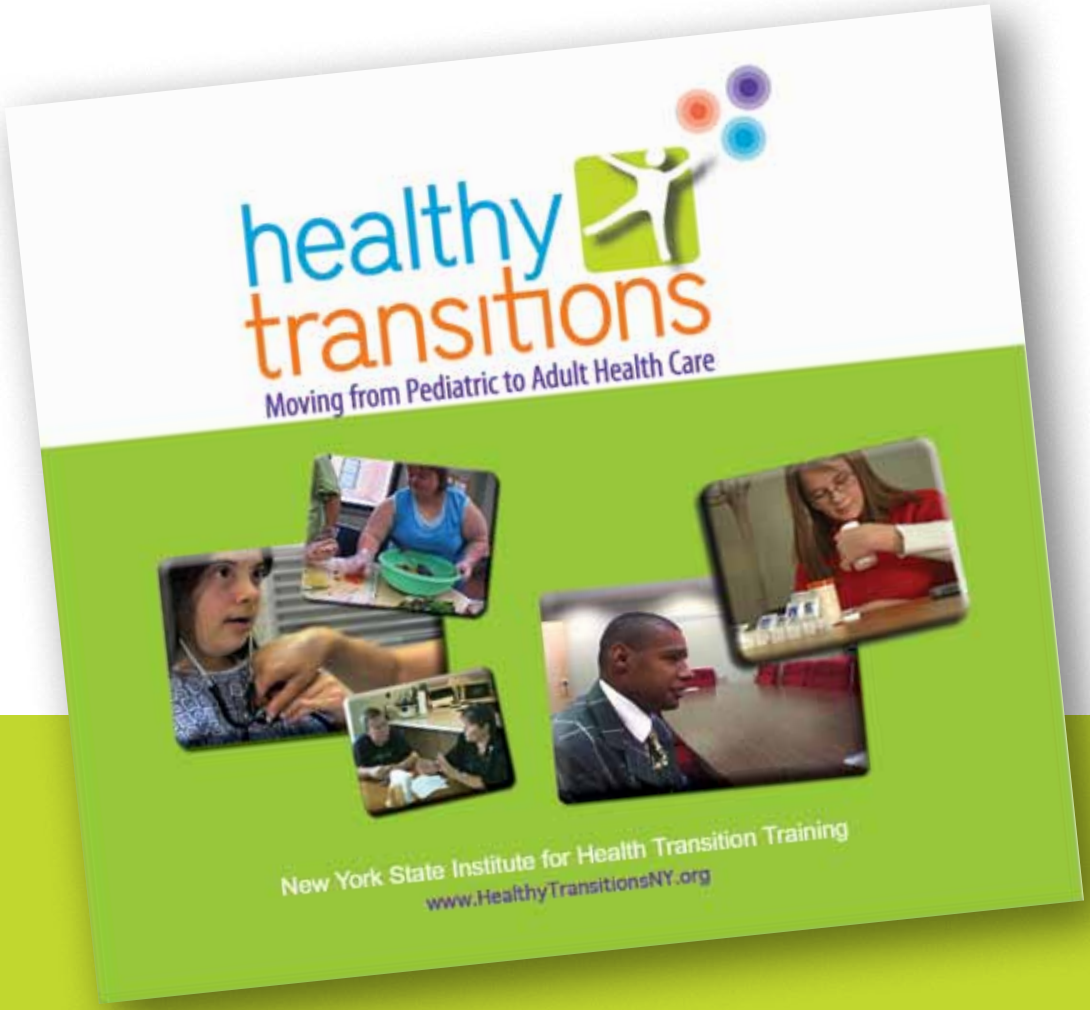
Notes

Notes



The videos are available on DVD or may be downloaded from HealthyTransitionsNY.org

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