

Finding Community Resources

Moving from Pediatric to Adult Health Care

Continuing Education Module



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 find community resources.

Finding Community Resources:

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

-  List family members and friends (“Circle of Support”) who can help with informal networking and accessing resources in the community.
-  Participate in meetings to develop a Transition Individualized Education Plan at school.
-  State what a VESID counselor does.
-  Describe services that are offered at Independent Living Centers.
-  List ways in which the Office for People with Developmental Disabilities can help during the transition from home to community living.

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!

Carrie

Carrie is a 25-year-old woman who has an intellectual disability. She graduated high school with an IEP diploma at the age of 21. She is not currently employed. Carrie would like to find a job.

Carrie recently joined a discussion group run by Self Advocates of New York State. This has helped Carrie to identify her interests, and to set priorities and goals for herself.

Members of the Self Advocates group share experiences and give practical advice to one another. They suggest that Carrie contact the New York State Vocational and Educational Services for Individuals with Disabilities (VESID) to find out about employment options.

Carrie received VESID services when she was in high school but her case was “closed” several years ago when she found a job, which she has since lost. Because it has been more than 2 years since Carrie was enrolled in VESID, the application process is repeated. She is invited to an orientation session. Because Carrie’s medical and psychological reports are more than 2 years old, new evaluations must be obtained.

Once these have been reviewed and approved, Carrie is re-enrolled in VESID.

Carrie is assigned a job coach who helps her to find a job at a local business. They meet on a regular basis to make sure that this is a good fit for Carrie. Once Carrie is established at her job, VESID “closes” her case. Carrie knows she can contact VESID anytime to re-open services, if needed.



Finding Community Resources

Learning Objectives:

1. Be familiar with role of high schools and Vocational and Educational Services for Individuals with Disabilities (VESID) during the transition from school to work.
2. Recognize regional Independent Living Centers (ILC) as a resource for advocacy, and peer counseling for youth.
3. Be aware of the Office for Persons with Developmental Disabilities (OPWDD) system as a resource for persons with developmental disabilities across the lifespan.
4. Understand how Self Advocates of New York State can foster self-determination among adolescents and young adults during the transition process.
5. Be familiar with Parent-to-Parent as a resource for advocacy and social support for family caregivers during the transition process.



Three Domains of Transition

The transition to adulthood is a period of complex physical, social, and emotional change. It is a process that involves learning to move from:

- **School to work**
- **Home to community living**
- **Pediatric to adult healthcare**

Moving from school to work is often the most meaningful transition domain for youths. Health care transition is rarely a top priority. Yet, without a seamless transition to the adult health care system, avoidable health complications can easily derail a young person's life at a critical time for social development. This can lead to a cycle of unemployment, under-insurance, inadequate housing, social isolation and further health complications. The fact is that outcomes are often interrelated across the three transition domains. Recognizing this is essential during the transition to adulthood.

Funding Streams

Although transition goals are often interrelated across domains, funding streams and services tend to focus on a specific area (see Table below). For example, funding for the transition from school to work is operationalized via New York State's Vocational and Educational Services for Individuals with Disabilities (VESID), and local school districts and/or Disability Support Services for matriculated students in post-secondary education programs. Services related to the transition from home to community living are available at regional Independent Living Centers and via the New York State Office for People with Developmental Disabilities, as are funding and programs relevant to the transition from pediatric to adult health care. Social Security Income (SSI) is a funding stream that is relevant to all three transition domains. This is because individuals who qualify for SSI automatically qualify for a variety of other income-based services. Detailed information about SSI is available in the module entitled "Getting Health Insurance." Community resources relevant to the transition from pediatric to adult health care are discussed in the module entitled "Looking Into Service Coordination". This module will primarily focus on community resources relevant to the transition from school to work and the transition from home to community living.

Key Funding Streams for Three Transition Domains

1. School to Work

- Vocational and Educational Services for Individuals with Disabilities (VESID)
- School districts (high school)
- Disability Support Services (college)

2. Home to Community Living

- Independent Living Centers (ILC)
- Office for People with Developmental Disabilities (OPWDD)

3. Pediatric to Adult Healthcare

- Office for People with Developmental Disabilities (OPWDD)
- Social Security Income (SSI)

Informal Networking

It is important to know about key programs and services (i.e. funding streams) that serve youths who have developmental disabilities during the transition years. However, it is equally important to tap into informal networks for support during the transition process. Parent to Parent of New York State is an excellent resource for family caregivers. Self Advocates of New York State is a grass roots organization for youths who have developmental disabilities that can help youths to create a “Circle of Support” during the transition years.

Informal networking can be very helpful when accessing services. Tips from parents or friends can help youths to get the most out of various programs and services that are available in the community. Advice from others who have “been through the system” can help youths and parents to understand options and navigate services and programs effectively.

Transition from School to Work

High schools have a formal mechanism for planning the transition from school to work for students who have developmental disabilities. This is called the Transition Individualized Education Plan (IEP). The Individuals with Disabilities in Education Improvement Act of 2004 (IDEIA) is a federal law that requires schools to develop a Transition Plan beginning at age 16. The focus of programming during the subsequent five years (graduation occurs at age 21 with an IEP diploma) is the preparation for employment and/or the development of other meaningful life skills. Many school districts offer excellent training opportunities in the community during the last five years of high school. Skills relevant to all three transition domains, such as personal hygiene, safety, communication, social skills, and practical skills such as the ability to navigate public transportation, can be written into the Transition IEP and developed at this time. The table on the next page provides an overview of the scope and services covered in a Transition IEP. Sample health related goals that can be included on a Transition IEP are listed below:

- Carrie will follow a picture schedule to take her medications
- Carrie will use her iPad to communicate her medical concerns at doctor’s appointments
- Carrie will direct her personal care attendant when assistance is needed for repositioning.
- Carrie will practice calling in her own prescription refills
- Carrie will tell medical staff about her latex allergy
- Carrie will schedule a Medicaid taxi to medical appointments

Components of the Transition Individualized Education Plan:

- **Post School Outcome Statements:** addressing post-school employment, post secondary education, and community living aspirations of the student.
- **Present Levels of Performance (PLP):** including a summary assessment of the student’s needs for transition services. PLP should identify the skills necessary for educational success as well as success in the work place and in community living.
- **Goals and Objectives:** including instructional services and community learning experiences focused on the development of transition skills, knowledge and abilities.
- **Related Services:** including instructional and community learning services to develop transition skills, knowledge and abilities, as appropriate.
- **Participating Agencies Information:** including Agency Name, Service Being Delivered, and Implementation Date of Services
- **Coordinated Set Of Activities: Instruction;** Community Experiences; Employment; Post secondary Education; Related services; Activities of Daily Living; Functional Vocational Evaluation

It is appropriate for youths to participate at CSE meetings to develop the Transition IEP. This way self-determination drives the transition process. Families may also request that VESID counselors participate in transition meetings. Transition specialists affiliated with Regional Special Education Technical Support Centers (RSE-TASC) can also be enlisted to develop high quality transition programs. Regional Special Education Technical Support Centers (RSE-TASC) are part of a statewide system that supports special education programs in rural school districts affiliated with the Boards of Cooperative Educational Services (BOCES) and in each of the “Big Five” school districts (Buffalo, New York City, Syracuse, Rochester and Yonkers). RSE-TASC maintains an excellent website with resources relevant to school-to-work transition: <http://www.emsc.nysed.gov/specialed/transition/>. Accessing the expertise of regional transition specialists with RSE-TASC is another important strategy for making school-to-work transition a success.

Disability Support Services

Students who pursue post-secondary education may be eligible for services offered by their college’s Office of Disability Support Services. These services typically include counseling, tutoring, adaptations, and modifications. Disability Support Services are required under Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, which “levels the playing field” for students with physical, psychological, and/or learning disabilities. Documentation to qualify for these services varies but often includes a medical diagnosis and/or psycho-educational reports. Enrollment is voluntary. It is up to the youth to establish contact with the Office of Disability Support Services. This is a change from high school, where disability related supports are integral to the Individualized Education Plan. “Think College” is an excellent resource with a wealth of information for youths, parents, and professionals about college options for people with intellectual disabilities: <http://www.thinkcollege.net/>. “Disability Friendly Colleges” is a website with information for college students who have physical disabilities: <http://www.disabilityfriendlycolleges.com/>. “LDOonline” provides resources and links that are helpful for college students who have learning disabilities <http://www.ldonline.org>, and the Asperger Foundation International college guide <http://www.aspfi.org/college/> provides information for students with Aspergers.

Vocational and Educational Services for Individuals with Disabilities (VESID)

The New York State Office of Vocational and Educational Services for Individuals with Disabilities (VESID) is another key funding stream that supports the transition from school to work. VESID serves high school students as well as adults with disabilities who are interested in entering the workforce. VESID serves persons with a wide variety of disabilities including physical and intellectual disability, psychiatric conditions, traumatic brain injury, substance abuse, learning disabilities and much more. Individuals who are legally blind are served by a separate agency, the New York State Commission for the Blind and Visually Impaired. Detailed information on VESID’s role during the transition process, as well as forms, guidelines, and transition planning tools are available on the internet at: <http://www.emsc.nysed.gov/specialed/transition/home.html>. The table on the facing page lists services that are offered by VESID.



Services offered by VESID

New York State Vocational and Educational Services for Individuals with Disabilities

- ▶ A vocational assessment to help identify skills, abilities, and interests, possible job goals and services needed to get a job and live independently
- ▶ A physical and/or psychological examination to help understand how the disability affects the ability to work.
- ▶ Vocational counseling and career planning.
- ▶ Short-term medical intervention to improve one's ability to work.
- ▶ Training to learn job-related skills. This may include:
 - On-the-job programs
 - Job Coach services
 - College and university programs
 - Trade and business school programs
 - Personal adjustment programs
 - Work adjustment programs
- ▶ Transition services for high school students.
- ▶ Driver evaluation and training.
- ▶ Services during assessment or training, such as:
 - Special transportation
 - Attendants, note takers, and interpreters
 - Reader's Aid for matriculated college students
- ▶ Books, tools, and equipment that are needed for training or employment.
- ▶ Rehabilitation technology.
- ▶ Telecommunication aids and adaptive devices necessary for rehabilitation.
- ▶ Assistance with some costs of modifications needed for employment:
 - Work site modifications
 - Van or other vehicle modifications
 - Home modifications
- ▶ Training in job-seeking skills to learn how to:
 - Fill out a job application or develop a resume
 - Handle job interviews successfully
 - Develop other job-related skills
- ▶ Occupational licenses, tools, initial stock, and supplies for a small business.
- ▶ Job placement services to help find suitable work.
- ▶ Follow-up services to make sure the job is a good fit.
- ▶ Referral to independent living centers for:
 - Peer counseling
 - Advice on other benefits
 - Housing assistance
- ▶ Training in independent living skills
- ▶ Assistance in working with agencies such as the:
 - Social Security Administration
 - Department of Social Services
 - Office of Mental Health
 - Veteran's Administration

For more information about VESID: <http://www.vesid.nysed.gov/> <http://www.vesid.nysed.gov/>

Eligibility determination for VESID services

VESID provides vocational counseling and transition services beginning at age 14. VESID also assists adults with job training and supported employment. Persons with an Individualized Education Plan, a 504 Plan, and even those who are on track to receive a Regents diploma can access VESID. However students with an IEP diploma must obtain a Graduate Equivalent Diploma (GED) in order to go to an adult training program or to seek a college education. It is case by case and there isn't a cookie cutter answer for each person that applies. The table on page 8 summarizes the eligibility determination process for VESID.

There is no cost for meeting with a VESID counselor or for anything related to the eligibility determination process such as medical examinations, vocational testing, and other assessments. There is also no cost for job placement services. Eligibility for other VESID services is income-based. This can be an area of confusion for some families. Generally speaking, youths who qualify for SSI meet income eligibility criteria for VESID services

Eligibility Determination for VESID (allow 60 days)

New York State Vocational and Educational Services for Individuals with Disabilities

Physical or Mental Impairment. The VESID counselor is required to document a permanent and/or a progressive impairment with accompanying functional limitations. Ideally, current medical and education records (i.e. not older than 2 years) are available for review. Counselors may request additional medical documentation. SSI recipients are automatically presumed to be eligible. Verification is requested and can be obtained by calling the SSA 800 number (1-800-772-1213) to request a current statement of benefits.

Impediment to Employment. The VESID counselor must also document that the disability is an impediment to employment and that it affects vocational functioning and activities.

Benefit from Services. The VESID counselor begins with the assumption that all persons benefit from services. However, if the counselor believes that the individual will not be able to achieve an employment outcome due to the severity of the individual's disability, a Trial Work Experience (TWE) or Extended Evaluation by two qualified rehabilitation counselors is required.

Requirement of Services. The VESID counselor makes decisions regarding whether services are required; what services are required; and why the services are required. Factors such as education, current employment, work history, motivation, vocational counseling issues, employer resistance, employment opportunities, responsibility of other agencies, transferable skills, and availability of comparable benefits are considered.

Possible Outcomes:

Eligible.

The individual is notified of the decision via an *Eligibility Letter* and planning for services continues.

Ineligible. *

- a. There is no impairment.
- b. There is no impediment to employment.
- c. The Trial Work Experience provides evidence that the individual cannot benefit from vocational rehabilitation services in terms of achieving an employment outcome.
- d. The individual does not require services.

** An individual who receives SSI can only be deemed ineligible under category c.
Persons who receive SSI cannot otherwise be denied VESID services.*

For more information about VESID: <http://www.vesid.nysed.gov/>

Transition from Home to Community Living

The transition from home to community living is a process that can take years or even decades. It can be an uncomfortable topic for many families, because it involves “letting go”. However, with a person-centered approach, the transition from home to community living can be an exciting and creative experience that fosters personal growth and confidence. Conversely, without planning, sub-optimal living situations, or even institutionalization, can occur. The University of Minnesota’s Research and Training Center on Community Living provides research, evaluation, training, and technical assistance for community living initiatives. The website is an excellent resource for youths, families and professionals: <http://rtc.umn.edu/main/>. Beth Mount’s work on person-centered planning is also a good source for inspiration: <http://www.capacityworks.com/>.

Finding community resources for the transition from home to community living is best framed in a positive light, as an opportunity to be pro-active. Planning allows everyone involved to develop skills and a basic comfort level with direct support professionals and other supports and services in the community. Familiarity builds trust and trust builds capacity for personal growth in the community. A person-centered approach is the key to fulfilling the aspirations of persons with developmental disabilities to live full, productive and integrated lives in their communities. When this is achieved, there is nothing better!

Independent Living Centers

Independent Living Centers are non-residential, private, non-profit, community-based organizations that provide services and advocacy by and for persons with all types of disabilities. At least half of employees at Independent Living Centers are persons who have a disability. These individuals can be powerful role models for youths who have disabilities.

Staff at Independent Living Centers can assist youths with the transition process by helping to advocate for physical and programmatic access to housing. Independent Living Centers help youths to identify and work effectively with direct support staff, if needed, and to find person-centered housing solutions in the community. Independent Living Centers also provide valuable information about employment, transportation, recreational facilities, and health and social services. This is accomplished by “Information and Referral” as well as informal networking. Many Independent Living Centers also offer peer counseling and/or assist families with accessing mental health professionals who are disability-aware.

There are nearly 500 Independent Living Centers in the USA. In New York State, regional Independent Living Centers are funded by the Department of Education’s Vocational and Educational Services for Individuals with Disabilities Program (VESID). To find a regional Independent Living Center in your area, search the VESID website at: <http://www.vesid.nysed.gov/lsn/ilc/about.htm>.

Office for People with Developmental Disabilities (OPWDD):

The OPWDD is the State agency responsible for providing supports and services for individuals with developmental disabilities and their families. The OPWDD system is organized into 13 regional Developmental Disability Services Offices (DDSO). Contacting the local DDSO is the first step toward receiving services from the OPWDD. The eligibility determination process for OPWDD services is summarized on page 10. The OPWDD/DDSO is the primary funding stream for housing and support services related to community living for people with developmental disabilities. The table on page 12 lists types of community living support services available in New York State via the OPWDD. The table on page 13 lists residential options funded by OPWDD that are available to people with developmental disabilities in New York State.

Eligibility Determination for OPWDD Services

4 step process

1. Assemble Documents for Eligibility Determination

Who Can Help?

1. Office for People with Developmental Disabilities (OPWDD) Transmittal Form

http://www.omr.state.ny.us/wt/images/wt_transmittal_form.pdf

Check item #14 in section #4 if you are interested in service coordination

Anyone

2. Documentation of Cognitive Functioning

Kaufman Assessment Battery for Children

Leiter International Performance Scale

Stanford-Binet Scales

Wechsler Series of Intelligence Scales

Schools

Request copies of
Psycho-educational testing &
Individualized Education Plan
from school district.

3. Documentation of Adaptive Functioning (required if IQ >60)

AAMR Adaptive Behavior Scale (School version only)

Adaptive Behavior Assessment System

Comprehensive Test of Adaptive Behavior

Vineland Adaptive Behavior Scale

Developmental Pediatrician

Psychologist

4. Documentation of Qualifying Diagnosis

New York State Mental Hygiene Law, Subdivision 22 of section 1.03:

http://www.omr.state.ny.us/document/hp_brochures_factsaboutdd.jsp

Physician or Psychologist

Documents diagnosis and that
onset was prior to age 22

2. Submit Documents to Local Developmental Disabilities Service Office (DDSO)

Find your local DDSO on the OPWDD locator map: http://www.omr.state.ny.us/ws/ws_linemap.jsp

3. Eligibility Determination by the DDSO

1st Step Review DDSO responds in writing. There are three possible outcomes: 1) eligibility or provisional eligibility is determined; 2) request is incomplete and additional records are needed; or, 3) request is forwarded for a 2nd Step Review by an interdisciplinary team.

2nd Step Review Interdisciplinary team at local DDSO reviews all materials. There are three possible outcomes: 1) eligibility is determined; 2) request was incomplete and additional records are needed; or 3) eligibility is denied because individual does not meet criteria for Developmental Disability. In this case, a letter will be sent to the family offering a face to face discussion, 3rd Step Review, or a Medicaid Fair Hearing.

- A Medicaid Fair Hearing is only offered if Medicaid funded services were requested on the Transmittal Form.
- Reviews usually take place within 90 days. Reply promptly if you are asked for more information.
- Contact your local Developmental Disabilities Service Office (DDSO) for questions or if there is a delay.

3rd Step Review The Eligibility Committee, at the New York City Regional Office or at the Upstate Regional Office in Albany, reviews materials and forwards its recommendation to the local DDSO.

The local DDSO informs the family of any changes. The DDSO decision is final unless the family requests a Medicaid Fair Hearing. Medicaid Fair Hearings take place at the NYS Office of Temporary and Disability Assistance. The hearing only resolves the single issue of developmental disability diagnosis. The family must make the request for a hearing within 60 days of Notice of Determination. The OPWDD does NOT schedule the Medicaid Fair Hearing.

4. Access OPWDD Services and Establish Service Coordination

- For a list of OPWDD services go to: <http://www.omr.state.ny.us/ws/servlets/WsNavigationServlet>
- Call local agencies or contact your local DDSO to set up service coordination:
http://www.omr.state.ny.us/wt/manuals/mscvm/wt_msc_coordinators.jsp

Note: The Enrollment in Medicaid Waiver requires additional paperwork. A service coordinator can help with this.

Transition from Pediatric to Adult Healthcare

The OPWDD/DDSO is the primary system for accessing habilitation services for adults with developmental disabilities. Because there is a natural overlap between habilitation services and medical care, the regional DDSO is one of the most important community resources during the transition from pediatric to adult healthcare. The module entitled “Looking into Service Coordination” provides detailed information about the array of health-related services and supports provided by the OPWDD to people who have developmental disabilities. The module entitled “Getting Health Insurance” provides information about the Home and Community Based Service waiver and other OPWDD-funded health care programs and habilitation services.

Self Advocacy Association of New York State (SANYS):

The Self-Advocacy Association of New York State, Inc. (<http://www.sanys.org/index.html>) is a not-for-profit, grassroots organization run by and for people with developmental disabilities. The goal of this organization is to help youths create a person-centered and person-directed system of supports. Regional SANYS meetings offer youths an opportunity to network with one another during the transition years. SANYS helps youths to identify a “Circle of Support”. A “Circle of Support” is an informal network of family, friends, neighbors, employers, etc. who meets regularly to provide informal support and advice during the transition years. A “Circle of Support” helps youths to identify and achieve individual and specific goals, as opposed to accessing programs and pre-determined services. Although a “Circle of Support” is not formally recognized by the courts, and does not come with a funding stream, tapping into this informal support network can be a very effective way for youths to achieve their goals and dreams.

Parent to Parent of New York State

Parent to Parent of New York State (<http://www.parenttoparentnys.org/>) is a grass roots organization with regional offices across the state that offer support, information, training, and advocacy for parents of children with special needs. Parent to Parent’s matching program gives parents/caregivers the opportunity to connect one-to-one with a parent/caregiver of an individual with the same or similar disability or special health care need. Parent to Parent links parents with other parents who have “been there”. Like SANYS, Parent to Parent helps to build a “Circle of Support.” A quote from the welcome page for the Parent to Parent website summarizes how helpful this organization can be during the transition years:

“We believe in the power of parents and family members helping each other. We believe that this connection among parents and family members reduces isolation, increases acceptance, and fosters the pursuit of dreams through the sharing of experience and information.”

In Summary

Finding community resources is an essential skill during the transition to adulthood. It’s important to know how to access major funding streams for each of the three transition domains:

- 1. School to work (VESID)**
- 2. Home to community living (Independent Living Centers, OPWDD)**
- 3. Pediatric to adult healthcare (OPWDD, SSI)**

Outcomes are often interrelated across the three transition domains. Recognizing this is essential to successful health care transition. Informal networking offered by grassroots organizations such as Self Advocates of New York State and Parent to Parent of New York State can help families to navigate these systems.

Community Living Support Services

That are Funded by New York State Office for People with Developmental Disabilities (OPWDD/DDSO)

Consolidated Supports and Services (CSS) is an option used to create individualized services through person-controlled, portable budgets. CSS focus on four basic person-centered outcomes: living in the home of choice; personal growth via community participation; development of meaningful relationships; and health and wellness.

Residential Habilitation Services provide individually tailored supports that assist with skills related to living in the community. These supports include adaptive skill development; assistance with activities of daily living (hands-on); community inclusion and relationship building; training and support for independence in travel; transportation; adult educational supports; development of social skills, leisure skills, self-advocacy and informed choice skills; and appropriate behavior development to help the individual access their community. Residential Habilitation also may include program related personal care, health care and protective oversight and supervision.

Individual Support Services (ISS) provide assistance to people with developmental disabilities in locating, leasing, or buying individualized living arrangements that are alternatives to traditional group living. Residential options include home sharing, independent living, HUD rental subsidy programs, low income home ownership programs, and other leasing and ownership initiatives.

Assistive Technology (Environmental modifications and adaptive devices) that is necessary to increase or maintain a person's ability to live at home with independence is also covered under Individual Support Services. These adaptations address needs related to physical, behavioral, or sensory disabilities in order to assist the person in communication, self-care, work, play/leisure activities, or physical exercise.

Family Support Services are designed to assist families in providing care for their loved ones with developmental disabilities who live full-time in their family home. Within each regional DDSO, there is one or more Family Support Consumer Council that is a partner with the DDSO in planning, developing and evaluating services on the local level. Services may include counseling, recreation, camps, after school programs, sibling services, and transportation.

Respite Services provide temporary relief from the demands of care giving, which helps reduce overall family stress. This often enables families to better meet the needs of their loved one with a developmental disability. Respite can be provided in the home or out of the home, during the day, evenings or overnight. Respite is an "indirect" service that provides relief to individuals who are responsible for the primary care and support of an individual with a developmental disability.

Crisis Intervention helps when a family member or loved one becomes ill, or when other difficulties arise. At these times it can seem that the only option is a costly and emotionally difficult out-of-home, residential placement. Crisis Intervention helps families to work through these situations so that family unity can be maintained.

For more information about OPWDD: <http://www.omr.state.ny.us/>

Residential Options

That are Funded by New York State Office for People with Developmental Disabilities (OPWDD/DDSO)

Family Care is a certified residential program that provides a structured and stable home environment within a family unit to a person with a developmental disability, offering support, guidance, and companionship. Family Care providers are home owners who receive a monthly stipend to care for individuals with developmental disabilities in their own homes.

Individualized Residential Alternatives (IRAs) are certified homes that provide room, board and individualized service options. There are two different kinds of IRAs.

Supervised Individualized Residential Alternative is a home that has staff nearby at all times that individuals are at the residence.

Supportive Individualized Residential Alternative is a home in which living is more independent and supervision is based on the person's needs for supervision; staff typically are not onsite at all times when residents are home.

Although IRA's for 10-12 individuals do still exist in New York State, the majority of group homes are designed for 2-3 individuals, to foster a home environment. Model group home programs that support individuals with autism, and group homes for individuals who have dual-diagnoses (developmental disability and mental health diagnoses) are being piloted in various communities throughout New York State. More information about these programs is available on NYActs website: <http://www.nyacts.org/> <http://www.nyacts.org/>.

Intermediate Care Facilities (ICFs) are residential treatment options in the community for individuals with specific medical and/or behavioral needs. ICFs provide 24-hour on-site assistance and training, intensive clinical and direct-care services, supervised activities and a variety of therapies. ICFs are designed for individuals whose disabilities severely limit their ability to live independently.

24-Hour Nursing Residences for Medically Frail. These residences are 24-hour supervised, small group homes that may be certified as Intermediate Care Facilities for people with developmental disabilities (ICF/DD) or Individualized Residential Alternatives (IRAs). In addition to enriched direct support staffing, they include either a Registered Nurse (RN) or Licensed Practical Nurse (LPN), and 24-hour on-call RN support. These homes are fully accessible; can provide for most types of chronic nursing needs, with the exception of ventilator care; and offer a more individualized alternative to a nursing home.

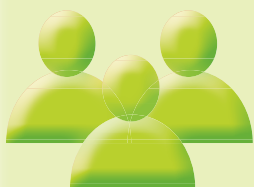
Integrated Group Homes are certified residential IRAs and ICFs that serve both aging and younger individuals in an integrated setting.

For more information about OPWDD: <http://www.omr.state.ny.us/>



**Adolescent/
Young Adult**

- Touch base with local SANYS Chapter to get started with a "Circle of Support".
- Contact VESID in high school and/or Disability Support Services at college.
- Participate in developing the Transition IEP. Request VESID services such as transportation training be added to IEP goals.



Family

- Contact Parent to Parent of NYS for training sessions and/or emotional support during the transition years.
- View transition planning as an opportunity to be pro-active, rather than merely "letting go".
- Advocate for a high quality Transition Individualized Education Plan in High School by accessing the expertise of transition specialists with the RSE-TASC system: <http://www.emsc.nysed.gov/specialed/transition/>.
- Become familiar with the scope of transition related services in your community by browsing the Transition Resources Directory maintained by HealthyTransitionsNY.org: <http://www.healthytransitionsny.org/company/result>



**Health Care
Providers**

- Document developmental disability to determine eligibility for VESID and OPWDD funded services.
- Refer parents to Parent to Parent of New York State.
- Refer youths to Self Advocates of New York State.



**Service
Coordinators**

- Share information about community resources for each of the three transition domains with youths and families. Help families to view the transition from home to community living as an opportunity to be pro-active by fostering a person-centered approach to planning.
- Encourage informal networking among families.
- Refer youths and parents to Transition Resources Directory maintained by HealthyTransitionsNY.org: <http://www.healthytransitionsny.org/company/result>

References and Resources

School to Work Transition

VESID:

<http://www.vesid.nysed.gov/>

NY Acts (Autism)

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

Asperger Foundation International College Guide (Asperger)

<http://www.aspfi.org/college/>

Think College (Intellectual Disability)

<http://www.thinkcollege.net/>

Disability Friendly Colleges (Physical Disability)

<http://www.disabilityfriendlycolleges.com/>

LDOnline (Learning Disability)

<http://www.ldonline.org>

Transition Specialists affiliated with the Regional Special Education-Technical Assistance and Support Center System (RSE-TASC)

<http://www.emsc.nysed.gov/specialed/transition/>

Home to Community Living

Independent Living Centers

<http://www.vesid.nysed.gov/lsn/ilc/about.htm>

The University of Minnesota's Research and Training Center on Community Living

<http://rtc.umn.edu/main/>

OPWDD:

<http://www.omr.state.ny.us/>

Beth Mount Capacity Works

<http://www.capacityworks.com/index.html>

Informal Networking

Parent to Parent of New York State

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

Self Advocates of New York State

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

Independent Living Centers

<http://www.vesid.nysed.gov/lsn/ilc/>

Quiz

1. Which of the following is NOT true regarding New York State Vocational and Educational Services for Individuals with Disabilities (VESID)?

- a. VESID serves high school students as well as adults with disabilities who are interested in entering the workforce.
- b. All services provided by VESID are free to all who apply.
- c. Families can request that VESID participate in CSE meetings to develop a Transition Individualized Education Plan.
- d. VESID provides assistance in working with agencies such as the Social Security Administration; Department of Social Services; Office of Mental Health; and the Veteran's Administration.
- e. VESID provides driver evaluation and training.

2. At least half of the employees at a regional Independent Living Center are people with disabilities who can provide peer counseling (True or False)

- a. True
- b. False

3. Which of the following is NOT true regarding the Office for People with Developmental Disabilities (OPWDD):

- a. Only serves adults who have developmental disabilities.
- b. It funds community living support services and residential programs for adults who have developmental disabilities.
- c. It provides expertise and funding for home modifications that help people with developmental disabilities.
- d. The OPWDD system is organized into 13 regional Developmental Disability Services Offices (DDSO).
- e. The OPWDD assists family caregivers by providing respite services, family support services, and crisis intervention.

4. Which of the following best describes the Self Advocacy Association of New York State:

- a. A not-for-profit, grassroots organization run by and for people with developmental disabilities.
- b. A group of pro-bono attorneys who advocate on behalf of people with developmental disabilities
- c. An oversight committee for residential services and programs at the Office for People with Developmental Disabilities.
- d. A group of agencies and non-profits dedicated to ADA awareness.
- e. None of the above.

5. Which of the following best describes Parent to Parent?

- a. A grass roots organization with regional offices across the state.
- b. Advocates for parents of children with special needs.
- c. Links parents with other parents who have "been there".
- d. Conducts training sessions to help families with the transition process.
- e. All of the above.

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

Notes

Notes

A blank sheet of lined paper with horizontal blue lines and alternating light gray and white background bands. The lines are evenly spaced and extend across the width of the page. The background bands are also evenly spaced, creating a striped effect. The word "Notes" is written in a purple, cursive font at the top center of the page.

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