

NYC Transition Handbook

Planning Today For
Your Child's Tomorrow



NYCAUTISM
CHARTER SCHOOL

Creating **Possibilities.**

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Transition Planning

INTRODUCTION

Transitions are challenging for everyone at every stage of life.

Many families of children with autism have established routines, systems that work for their child and the rest of the family. As the end of school nears, these systems may no longer work beyond graduation. Families are faced with many concerns to think about. What government aid is available, if any? Will my child be able to work? Is my child ready for college? Are there programs that can help my child in college? Can my child live on his or her own? How do I prepare financially for my child's needs after high school? This process can feel overwhelming, but you are not alone.

Not every young adult with autism will go on to college. Some will get vocational training; some will work; some will go into day programs; and some will stay home. Regardless of the path they take, young adults with autism will become adults, both physically and legally.

For parents, that means preparing for profound changes in nearly every aspect of their children's lives – and for changes in their own role as well.

Building a new support structure requires sorting through a maze of options while also learning about a variety of new laws, systems, benefits, and requirements. Some sort of road map may help.

This aims to be that road map. Whether you have a young child (6–11), young teenager (12–15), or even a young adult (16+) this is a tool for you to use to plan for your child's transition into adulthood. While it can't cover every detail or every situation, it will give you an overview of what lies ahead and a list of resources for where to go next.



Transition Planning

Early Planning
Leads to Success

EARLY PLANNING

Planning for your child's future may seem a daunting and distant prospect.

Starting early will allow you to take smaller, more manageable steps, and help you and your child reach goals successfully with less stress. This handbook has been created to give you specific steps to take over the course of your child's development from a young child to early adulthood.

Transition Planning

Children Aged 6–11



Create and Keep a Record of Educational Documentation

This is a binder or pocket folder containing IEPs, assessments from therapists/related service personnel, bussing forms, home program documentation, vaccination records, and any individual records or correspondence with the Department of Education.

Why? First and foremost, in case you ever move or change schools, this will ensure that you have everything your child's next school needs to make the transition easier. Further, having these documents accessible will save you time at next year's IEP meeting, will show that you did request a limited-time bus route and provided suitable documentation, will remind you of how you completed the school lunch form last year, etc. If you have all these materials either physically at hand or digitally stored, you can reduce stress and increase efficiency.



Create and Keep a File of Medical Records

The same principles apply here, but your audiences and information security concerns are slightly different. Electronic health records help in terms of accessibility, but they do not eliminate the need for an archive.

Resources

Detailed guidance about both types of record archives is available from Parent to Parent of New York State, as a webinar and a publication including a model medical notebook:

Webinar Registration

<http://parenttoparentnys.org/index.php/site/form-training-registration>

PDF of the Notebook

http://parenttoparentnys.org/images/uploads/pdfs/Health_Care_Notebook_July_2010.pdf



Obtain OPWDD Eligibility and Enroll in Home & Community Based Services (HCBS) Medicaid Waiver

In New York State, Medicaid does far more than provide medical coverage to low income New Yorkers. Medicaid also provides access to funding for WAIVER SERVICES through OPWDD (Office of People with Developmental Disabilities), the state agency responsible for overseeing services not under the domain of the school system for individuals with developmental disabilities. Such services include respite, camp, after-school and weekend programs, community habilitation and more. Additionally, it is the state agency that will be responsible for determining the services your child may receive after transitioning out of the school system at the age of 21.

It is important to note that for children under the age of 21, family income does NOT matter with regard to eligibility for Medicaid. So, although you and your family may not otherwise be Medicaid eligible, your child may qualify for OPWDD services through the Medicaid waiver because income eligibility is waived in this instance.

It is important to have your child deemed eligible prior to his or her twenty-first birthday.

Benefits to Medicaid Waiver Enrollment:

- Access to recreation, respite, and in-home support for families needing support beyond the school environment.
- It is a requirement for the residence portion of all residential school placements if that's a potential future direction for your child.
- Funds adult supports and services (except for some employment programs) following graduation or after June of the school year in which your child turns 21.

Resource

Details about how to enroll and borough-wide contact information can be found at
<http://www.opwdd.ny.gov>



Foster Independence

Assign Chores

One area in which parents of children with developmental disabilities tend to underestimate their child's abilities is household chores. Many may think their children will take too long to get the job done, that the tasks will be too hard or that they should do everything for them because they have a disability.

Everyone should make a contribution at home, and though chores should be adjusted for your child's specific abilities and carefully chosen so they don't make MORE work for you, they should become part of your child's routine.

Identify and Participate in Leisure Activities

It may take many attempts to find the right match, but a favored leisure activity is a powerful incentive to get your child out into the community. At a minimum, doing so will provide them with the health benefit of getting physical exercise. And the standards for acceptable behavior are considerably looser in certain leisure activities, which can pave the way for inclusive community relationships. Running with the Achilles Track Club, walking a dog, or planting a community garden plot will put your child in an environment with people who have shared interests that could turn into natural supports in your community.

Transition Planning

Children Aged 12–15



Increase Responsibilities and Independence at Home

For adolescents, completion of chores can be tracked and acknowledged with whatever privileges are most motivating for your child. This might be getting points toward a special prize or earning an allowance.

Most importantly, completing chores can give a sense of accomplishment and mastery. And chores teach children that responsibility is a part of life. Chore completion by children also gives parents the opportunity to overcome some of the over-protectiveness that they may often feel.



Transportation

Children are likely to be eligible for a half-fare MetroCard (which also provides them with photo identification). These can be used as pay-as-you-go, value-added on a monthly basis, or autofill with a credit card.

Access-A-Ride is an alternative for children who have behavior issues on the bus or subway. It also serves destinations beyond the bus and subway maps. Obtaining eligibility for Access-A-Ride requires a visit to their facility and review by a clinician.

Resources

MTA accessible transit website
<http://web.mta.info/accessibility/transit.htm>

Half-fare MetroCard Disability Application
<http://web.mta.info/nyct/fare/pdf/disabled.pdf>

Access-A-Ride
<http://web.mta.info/nyct/paratran/guide.htm>



The IEP & Transition Planning Process

As part of the IEP process, specific tasks are required at various points of your child's education to plan for their uninterrupted passage from school to post-school activities. These post-school activities include post-secondary education, vocational education, integrated employment, continuing and adult education, adult services, independent living and community participation. Goals will be developed based on your child's strengths, needs, preferences, and abilities, as well as your desires.

Beginning at age 12, the NYC DOE Level 1 Vocational Assessment can be completed. This consists of a student (when appropriate), parent and teacher interview. This assessment helps with identifying a child's strengths, needs, preferences and interests.

Resources

To access forms and detailed explanations go to:
<http://www.p12.nysed.gov/specialed/transition/level1careerassess.htm>

Another document that is designed for students with autism which can be helpful can be found at:
<http://www.autismspeaks.org/family-services/community-based-skills-assessment>

At age 14, the transition planning process formally begins. The IEP must include a coordinated set of activities, related services, and community experiences, as well as employment and other post-school adult living objectives. If appropriate, statements about a student's acquisition of daily living skills and functional vocational skills should also be included.

At age 16, the IEP must include Measurable Postsecondary Goals in the areas of Community Integration, Employment, and Daily Living. These goals will be developed based on your child's strengths, needs, preferences, and abilities, as well as your desires.

Resource

<http://schools.nyc.gov/documents/d75/iep/Continuum%20of%20Services.pdf>

Additional Steps Parents/Families Can Take:

- Visit a family support fair in your borough.
- Attend monthly transition committee meetings in your borough.
- Participate in the opwdd council in your borough.
- Review guardianship and estate planning issues.
- Talk to your child about their disability and medical management needs (as needed).
- Learn about resources (e.g., Acces-vr, opwdd, and/or educational opportunities).



Participate in Community Activities/Events

Many publicly and privately funded programs focus on youth development, so now is the time to identify programs that promote inclusion and are based on shared interests. Making community connections now may help your child more fully integrate and participate in his or her community.

Transition Planning

Young Adults Aged 16–21



Planning for the Future While Still in School

As the transition age of 21 approaches, it is wise to focus attention on preparing for future settings. Supports and resources get much leaner down the road, so you should not let yourself, your child, or his/her school coast to the finish line.



Graduation Options to Consider

New York State has recently made changes to high school graduation options for students with disabilities. As before, students with disabilities may graduate high school with a Regents, Advanced Regents, or Local Diploma. Students who do not meet the requirements for a Regents or Local Diploma may exit school with either a Skills and Achievement Commencement Credential (SACC) or a Career Development and Occupational Studies (CDOS) Commencement Credential. These credentials replace the “IEP Diploma,” which is no longer being offered. All diploma and credential options available to students with disabilities are described further below.

Diploma Options

Graduating with a high school diploma gives students access to college, the military, and trade schools. The two most common diplomas in New York State are the Regents and Local Diplomas.

Regents Diploma

The Regents diploma is awarded to high school students who earn 44 credits in different courses and receive a passing score of 65 or higher on five Regents exams (English, Math, Global Studies, U.S. History, and Science).

Local Diploma

The Local Diploma is available only to students with IEPs or Section 504 accommodation plans who earn 44 credits in specific courses and meet specific testing requirements. For students with 504 accommodation plans, their plans must specify that they are eligible for the Local Diploma. The testing requirements available to students depend on the year they started high school.

Non-Diploma Options

Students with IEPs who are unable to earn a

Regents or Local Diploma may graduate with one of two new credential options mentioned above, the CDOS Commencement Credential or SACC. Neither of these credentials is equivalent to a regular high school diploma. The CDOS Commencement Credential and the SCAA CANNOT be used to apply to college, the military, or trade schools. They are new credentials, so it is not yet known how potential employers will view them.

Career Development and Occupational Studies (CDOS) Commencement Credential

The CDOS Commencement Credential is a certificate that is intended to indicate a student’s readiness for entry-level jobs. The CDOS Commencement Credential is available to students with IEPs who are not assessed using the New York State Alternate Assessment (NYSAA). The CDOS Commencement Credential can be awarded either in addition to a Regents or Local Diploma or to a student with an IEP who is unable to earn a diploma.

Resource

More information about the CDOS can be found through the NYS Department of Education:

<http://www.p12.nysed.gov/specialed/gradrequirements/CDOS-QA-1113.htm>

Skills and Achievement Commencement Credential (SACC)

The SACC is available only to students with severe disabilities who take the New York State Alternate Assessment (NYSAA). Students receive a certificate along with a Student Exit Summary, which documents the following:

- The student’s skills, strengths, and interests.
- The student’s level of achievement of the New York State CDOS standards.
- The student’s level of academic achievement as measured by NYSAA.

Resource

Additional information about the SACC can be found here:

<http://www.p12.nysed.gov/specialed/publications/SACCmemo.htm>



Government Issued Identification

This can be a passport, a non-drivers ID, or the new New York City Municipal ID. This type of ID is a real convenience for accessing services of all kinds, and a necessity for air travel. Your ability as a parent to provide documents which contribute toward the needed ‘points’ of required documentation with NYS DMV is far easier to document before your child is 18.

Resources

Non-driver ID card

<http://dmv.ny.gov/id-card/bget-non-driver-id-card-ndid>

NYC ID card

<http://www.nyc.gov/idnyc>

Transition Planning

Young Adults Aged 16–21



Guardianship or ‘Supported Decision-Making’

Throughout the United States, turning 18 brings the right to vote, to be responsible for contracts, to be fully accountable to law enforcement, and a surprising degree of patient privacy in healthcare. Because of this, many parents seek guardianship in order to continue to have some control over decision-making for their child. In New York, the form of guardianship that many families choose is titled 17A Guardianship, and it is sought with the Surrogate’s Court in your county of residence.

Note: Guardianship is under legislative review and may be reformed in the coming years.

The most common reason to pursue guardianship is to ensure oversight to medical care that comes with even small risks requiring the patient or someone on their behalf to give informed consent. Sometimes, needed medical interventions are actually withheld because the patient is not capable of exercising informed consent and no one else has been assigned that responsibility. And there are other, hopefully rarer contexts, including contracts and law enforcement, where guardianship provides the guardian with the right to void contracts, have access to information or be involved in decision-making.

However, advocates for those with Intellectual and Developmental Disabilities have been pressing for some time for a shift toward ‘supported decision-making’, which is seen as more flexible and less a removal of rights for the person under guardianship. In New York State, persons under guardianship retain the right to vote.

Guardianship

Resource

Learn about guardianship options in NY State and options to consider before proceeding:

<http://www.rcal.org/services/guardianship-and-your-child/>

If guardianship is a certainty, it is ideal to begin the process about a year before the child turns 18 years of age.

Resource

Forms are available for download from the State of NY Courts website at:

<http://www.nycourts.gov/courthelp/DIY/guardianship17A.shtml>

Family and estate lawyers will prepare a petition for guardianship, but for most people it is a realistic do-it-yourself project.

Resource

New York Lawyers in the Public Interest offers workshops for completing the application to Surrogate’s Court:

<http://www.nylpi.org>

Either with or without a lawyer, the most information-intensive part of the application is compiling a list of all the residential addresses of the person or persons applying for guardianship and any person over 18 residing in their household, going back 28 years. This is required to facilitate a criminal background check for all adults in the house where a person under guardianship is likely to reside.

Resource

AHRC offers assistance with the guardianship application, and has a brochure available here:

<http://archive.constantcontact.com/fs110/1103862535052/archive/1114276174172.html>

To seek free assistance for the process, you will need to get on the agency’s list more than a year in advance.

Supported Decision-Making

If the child has the communication skills and some capacity to understand risks, supported decision-making may be a more appropriate alternative to guardianship. Many adults with disabilities have strong feelings about maintaining control over decision-making and the resulting conflict can create a bigger problem than the one it is trying to address.

Fortunately, the State of New York has tools that allow a person to make health care decisions and obtain health care information, while still allowing an individual decision-making rights in other areas. These include a Health Care Proxy, a durable power of attorney, and a HIPPA release. These documents are good for every adult of any level of functioning who may become incapacitated through illness or trauma.

In practice, most health care providers recognize a named health care proxy, person with power of attorney for health care, or HIPPA release as someone who is providing decision-making support to the patient and will require information to carry out that responsibility both now and in the event of incapacity. But the patient always has the option to request privacy in health care, as that decision stays with them.

Transition Planning

Young Adults Aged 16–21



Benefits

Social Security

At age 18, individuals are eligible to receive income support and medical insurance through federal benefit programs.

Children with autism may be eligible for Supplemental Security Income (SSI) disability benefits if their family's income and assets don't exceed the SSI limits.

Adults with autism can apply for SSI or Social Security Disability Insurance (SSDI); however, SSDI is available only to those with a work history from jobs that paid Social Security taxes.

An "adult child (age 18)" of a parent receiving Social Security retirement or disability benefits (meaning a child over the age of 18 who has had autism before turning age 22) can get SSDI benefits on the earning record of the parent.

Resource

Official Social Security Website

<http://www.ssa.gov>

Adult Health Care

Under the Affordable Care Act, there is the possibility to continue to provide coverage for children through a parent's own medical insurance until age 26.

Adult health concerns are different than those of children and most pediatricians will push patients out of the nest at some point. Even if your child will be able to continue with a family practitioner who can work with adults, some expectations of the adult patient will change.

Resource

Got Transition Website

<http://www.gottransition.org>

Draft Registration (Males Only)

Almost all male U.S. citizens and male immigrants, who are 18 through 25, are required to register with Selective Service. Disabled men who live at home must register with Selective Service if they can reasonably leave their homes and move about independently. A friend or relative may help a disabled man fill out the registration form if he can't do it himself.

Men with disabilities that would disqualify them from military service still must register with Selective Service. Selective Service does not presently have authority to classify men, so even men with obvious handicaps must register now, and if needed, classifications would be determined later.

Resource

Official Selective Service System Website

<http://www.sss.gov>



Marketing Skills

From early as possible, try to effectively educate people about your child's abilities and the accommodation he or she will require for success – it helps to build support for the future.

Instead of saying "John has autism," say

John struggles with (challenges)

John doesn't speak and learns from lots of practice

But offers (strengths)

He is strong and likes to put things in order

By seeking (supports)

If I can find a visual and repetitive task/job for him

For (success)

He will be a fast and productive worker

It's Never Too Early To Begin Planning

Planning for the day when school ends can be poignant, challenging, and sometimes overwhelming. Starting early and taking a step-by-step approach can empower you, and allow you to take control of the process. Transition planning is not about what is probable but rather, what is possible.

Stay Up to Date

Look to other parents who have gone before you and ask questions. Always be looking for information about adults with autism and follow organizations that serve them. Keep your eyes and ears open, to both the desired and unwanted outcomes.

Follow these organizations on social media to receive updates on successful adult transitions.

ORGANIZATIONS TO FOLLOW

Advancing Futures for Adults with Autism
www.afa-us.org

Autism After 16
www.autismafter16.com

New York Collaborates for Autism
www.nyc4a.org

YAI/National Institute for People with Disabilities Network
www.yai.org



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