

Neurodiversity: Transition to Adulthood Resource Packet

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Introduction

The transition from adolescence to adulthood is a pivotal and often challenging time for anyone. For individuals who identify as neurodiverse, including those with Autism Spectrum Disorder (ASD), these changes bring unique stressors that can significantly affect their quality of life. ASD, one of the most common neurodevelopmental conditions, affects approximately one in 34 people. The process of leaving the supports, safety, and predictability of school and childhood for potential college, the workplace, or independent living can feel daunting.

Transition planning should be a collaborative process involving the young person, their family, the Department of Education, and other appropriate agencies. The goal is to maximize individuals' self-determination, utilizing [person-centered](#) planning, and building the capacity for [self-advocacy](#)—the ability to speak and act on their own behalf. Core elements of transition include post-secondary education, employment, independent living, and community participation.

In New York, services provided through the Department of Education end at age 22. Beyond this, public services are offered through the Office of People with Developmental Disabilities ([OPWDD](#)), making early enrollment in OPWDD a critical component of transition planning. Without proactive preparation, many neurodiverse young adults and their families face uncertainty, particularly when navigating the complex healthcare system. Early identification and intervention are essential since youth with ASD face a higher risk of developing mental health conditions such as anxiety, depression, obsessive-compulsive disorder, and psychosis. These risks are often heightened during significant transitions.

This resource packet aims to address these challenges by equipping families and practitioners with tools and information to support neurodiverse individuals. By promoting preparation, continuity of care, and collaboration, the goal is to improve outcomes and empower neurodiverse individuals and their families through this critical journey into adulthood.

Early Transitions – Early Intervention

Early Intervention (EI) is a program that provides support and services to infants and toddlers with developmental delays or disabilities to enhance their growth and development. It aims to address developmental concerns early and is available for children from birth to age three. Importantly, ASD may be formally identified in EI and services including Applied Behavioral Analysis ([ABA](#)) begun.

According to NYC.gov, anyone can make a referral by filling out the EI Referral Form, available at: <https://www.nyc.gov/assets/doh/downloads/pdf/earlyint/ei-referral-form.pdf>

The completed form must be faxed to one of the numbers located in the “Referral Reason” section.

There are two referral options:

1. **Child with a suspected or known developmental delay or disability** living in any NYC borough.
2. **Child is developing typically but may be "at risk"** for atypical development, or the child missed or failed a newborn hearing screening.

Impartial Hearing Info Packet

Advocates for Children (advocatesforchildren.org) has been a reliable source of information. They provide informational packets on various topics, including impartial hearings. See Info Packet link: https://advocatesforchildren.org/wp-content/uploads/2012/01/impartial_hearings.pdf

Transition from EI to CPSE and CSE

Families should be aware that as children transition from EI to Committee on Preschool Special Education (CPSE) and then to Committee on Special Education (CSE – “Turning 5”) that a previous ASD identification will not be automatically carried forward, and [ABA](#) will not be provided as part of special education services. It is essential for strong advocacy efforts at these points to ensure that children with ASD and other neurodiverse conditions receive appropriate classroom placements (e.g. [Horizon](#) or [ASD Nest](#)) and services. If needed, [ABA](#) should be accessed through the child’s health insurance.

Parent Support

This flyer provides information about the LEND parent support group. The group meets monthly and serves as a resource for parents to connect and share information. Link to the flyer:

https://drive.google.com/file/d/1ICos715RXqx_NG8oos13hrFwW6kKFoYs/view?usp=drive_link

Healthcare Transition: From Pediatrics to Adult Medicine

The shift from pediatric to adult healthcare can be a challenging process for families, particularly when seeking providers who understand the unique needs of neurodiverse individuals. Many adult healthcare providers are not adequately trained or comfortable managing patients with neurodevelopmental disorders, which can result in missed or incorrect diagnoses of conditions such as anxiety, chronic pain, or gastrointestinal issues. For those with Medicaid coverage, limited access to providers often leads to long wait times and fewer choices.

It is essential to begin planning for this transition well before age 21. Effective collaboration between the pediatrician and the adult provider can ensure continuity of care and an individualized approach. An ideal adult healthcare provider takes a holistic view, addressing not only medical issues but also behavioral concerns, while considering the person’s broader needs. Families and young adults should prioritize finding a provider who fosters trust and confidence, enabling effective communication and advocacy for their healthcare needs.

Practical Tips for Transitioning to a new Adult Primary Care Provider for [Self-Advocates](#) and Families

Start Early: Transitioning from pediatric to adult healthcare is a critical process that requires thoughtful planning and preparation. Starting early, ideally between ages 12 and 14, allows families and providers to address key considerations such as the individual’s self-management skills, decision-making supports, and changes in insurance or waivers. Early planning ensures a smoother transition, minimizes gaps in care, and fosters independence in managing health needs. As the transition age varies by provider, discussions about timing should occur well in advance, incorporating tools like the Six Core Elements of Health Care Transition™ to guide the process (<https://www.gottransition.org>)

By ages 16 to 18, families should ensure key documentation, such as updated psychological testing and Individualized Education Program (IEP) records, is complete. This is especially important for states requiring adult disability determination through the Social Security Administration (SSA) for Medicaid.

At age 18, several critical tasks should be addressed:

- **Insurance:** Secure adult insurance coverage.
- **Disability Determination:** Complete adult disability determination through the SSA if required.
- **Decision-Making Supports:** Finalize legal arrangements, such as [guardianship](#) or power of attorney, if needed.
- **Health Maintenance:** Schedule a well visit and ensure vaccines are up to date, as adult clinics may not stock the same vaccines as pediatric providers.
- **Medical Records:** Prepare a comprehensive medical summary for the new healthcare team.
- **Accommodations Summary:** Develop a behavior support and accommodations summary that outlines helpful strategies for communication and adaptive care needs.

Many pediatric providers and subspecialists transition patients by age 19, and some may not accept new referrals for individuals over 18. Starting the process early helps families navigate waitlists, secure appropriate adult providers, and ensure continuity of care during this phase of life.

Ask for Recommendations: Your pediatrician can provide valuable referrals to adult primary care providers experienced with neurodiverse individuals. Community organizations, [self-advocates](#), and family advocacy groups are also excellent resources for finding providers who deliver personalized, high-quality care. Additionally, ask your insurance provider, home and community-based waiver service coordinator for further assistance in identifying suitable adult healthcare options.

Foster Communication: Effective communication between your child's pediatrician and the new adult care provider is essential to ensure continuity of care. Encourage the pediatrician to share detailed medical records, past treatments, and any specific approaches that have been successful in managing your child's health. A direct conversation between providers can help the new doctor understand your child's needs, reducing the stress of repeating medical histories.

Prioritize Comfort: Selecting a doctor who makes your child feel comfortable is crucial. A positive rapport with the new provider will encourage your child to express concerns, ask questions, and advocate for their own health needs. Practice role-playing appointment scenarios with your child to help them gain confidence in communicating with their new doctor. Feeling comfortable in a new office may take practice and several visits. Pictures of the new clinic or doctor, social stories, and videos can be particularly helpful in preparing your child for the transition. These tools can reduce anxiety and make the new environment feel more familiar and approachable.

Additional Tips:

- **Check Insurance Compatibility:** Ensure the doctor accepts your insurance or Medicaid to avoid unexpected costs.
- **Visit the Office in Advance:** If possible, arrange a preliminary visit or consultation to familiarize your child with the office environment and the provider.
- **Prepare a Health Summary:** Create a concise document summarizing your child's medical history, current treatments, and any specific concerns. This can be a helpful reference during the first few appointments when meeting with a new provider.
- **Leverage Technology:** Use patient portals and online tools to streamline communication and track appointments, prescriptions, and lab results.

Helpful Links for [Self-Advocates](#) and Families:

Navigating Mental Health and Life Transitions for Autistic Youth. A good overview of transition issues. <https://autismspectrumnews.org/navigating-mental-health-and-life-transitions-for-autistic-youth/>

Got Transition: Parent and Caregiver Resources

Specific tools for parents and caregivers to support their child's transition to adult healthcare. <https://www.gottransition.org/resource/?hct-family-toolkit>

Autism Speaks Healthcare Transition Toolkit

Step-by-step guidance for families navigating the move to adult healthcare services and additional elements related to transitions. <https://www.autismspeaks.org/tool-kit>.

National Alliance to Advance Adolescent Health: Healthcare Transition Resources

Tools and resources for families and providers to improve healthcare transitions for youth with chronic conditions. <https://www.thenationalalliance.org/>

From Pediatrics to Adult Healthcare: Considerations for Practicing Providers

Transition-age youth with neurodevelopmental disorders, such as ASD, often face additional medical challenges beyond their primary diagnosis. Common co-occurring conditions like gastrointestinal (GI) issues and epilepsy can significantly impact their physical health, behavior, and quality of life if not well-managed during the shift to adult healthcare. Providers play a vital role in ensuring continuity of care and implementing effective strategies for these transitions.

[Gastrointestinal \(GI\)](#) Issues in ASD

GI symptoms, such as constipation, diarrhea, abdominal pain, bloating, irregular eating (e.g., overeating or undereating), and restricted food choices, are prevalent in individuals with ASD and can lead to behavioral issues like irritability, sleep disturbances, and even self-injurious behavior if untreated.

Considerations for Providers:

- **Underdiagnosis:** Beware of [diagnostic overshadowing](#). Non-verbal patients may express physical discomfort through behavioral changes like aggression. Caregiver input on eating and bowel habits is crucial, and imaging like KUB x-rays can aid in diagnosis and are often well tolerated.
- **Medication Side Effects:** Medications for co-occurring conditions (e.g., stimulants, [antipsychotics](#), SSRIs) can cause GI symptoms like constipation or nausea.
- **Dietary Concerns:**
 - Parent-initiated diets:** Families may explore restrictive diets such as gluten-free or casein-free diets as a potential ASD treatment, though current evidence supporting their effectiveness is limited.
 - Self-imposed restrictions:** Many children with ASD limit their diets themselves, often preferring highly processed foods like chicken nuggets or pizza, which typically lack vegetables and fiber.

Recommendations for Providers:

- Regularly screen for GI symptoms and assess diet, water intake, and bowel habits.
- Collaborate with gastroenterologists for comprehensive care.
- Educate families on balanced nutrition and discourage unsupported dietary interventions.

Epilepsy in Neurodiverse Youth

Epilepsy is not uncommon in youth with ASD and developmental disabilities. Despite its prevalence, about 25% of individuals aged 18–25 with chronic conditions, including epilepsy, reported no healthcare visits in the past year.

Key Considerations for Providers:

- **Complex Care Needs:** Epilepsy often coexists with developmental or mental health conditions. Transitioning to adult neurologists experienced in these complexities should be prioritized.
- **Driving and Independence:** Discuss driving restrictions and alternative transportation with families, as these can impact a young adult's independence.
- **Transition Gaps:** Structured processes for epilepsy care are often lacking in pediatric systems, leading to treatment delays.

Recommendations for Providers:

- Implement structured transition plans, such as the Six Core Elements of Transition, to maintain continuity of care.
- Create individualized care plans addressing epilepsy management alongside co-occurring conditions.
- Foster independence by teaching young adults to manage prescriptions, appointments, and other aspects of their healthcare.

Helpful Links and Resources for Providers

American Academy of Pediatrics (AAP): Autism Toolkit

Resources and guidelines for clinicians managing care for children and adolescents with ASD.

<https://publications.aap.org/toolkits/pages/Autism-Toolkit>

Autism Speaks: Medical Conditions Associated with Autism

Information on co-occurring medical conditions in individuals with ASD, including GI issues and epilepsy.

<https://www.autismspeaks.org/medical-conditions-associated-autism>

Autism Treatment Network: Bringing Best Practices to All Children

An overview of best practices in medical care for children with ASD, including management of GI issues and epilepsy. [https://publications.aap.org/pediatrics/article/145/Supplement_1/S13/11547/The-](https://publications.aap.org/pediatrics/article/145/Supplement_1/S13/11547/The-Autism-Treatment-Network-Bringing-Best)

[Autism-Treatment-Network-Bringing-Best](https://publications.aap.org/pediatrics/article/145/Supplement_1/S13/11547/The-Autism-Treatment-Network-Bringing-Best)

Child Neurology Foundation: CNF's Transition of Care Toolkit*

Designed to empower youth and young adults with neurological conditions and guide providers through transition conversations. [https://www.childneurologyfoundation.org/wp-](https://www.childneurologyfoundation.org/wp-content/uploads/2020/10/CNF-2020-Transition-of-Care-Toolkit.pdf)

[content/uploads/2020/10/CNF-2020-Transition-of-Care-Toolkit.pdf](https://www.childneurologyfoundation.org/wp-content/uploads/2020/10/CNF-2020-Transition-of-Care-Toolkit.pdf)

ECHO Training Program coordinated by Dr. Ellen Jean Fremion:

<https://cpd.education.bcm.edu/content/intellectual-and-developmental-disabilities-2024>

Got Transition: Six Core Elements of Health Care Transition*

A comprehensive framework to guide providers in transitioning youth from pediatric to adult healthcare. <https://www.gottransition.org/six-core-elements/>

Mayo Clinic: Autism Spectrum Disorder and Digestive Symptoms

Information discussing the link between ASD and digestive issues, with management recommendations. <https://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/expert-answers/autism-and-digestive-symptoms/faq-20322778>

National Autistic Society: Epilepsy and Autism

Guidance on understanding and managing epilepsy in individuals with autism. <https://www.autism.org.uk/advice-and-guidance/professional-practice/epilepsy-autism>

The American College of Physicians (ACP): Pediatric to Adult Care Transitions Toolkit*

Provides disease-specific tools to assist clinicians in facilitating effective transitions for young adults with chronic conditions. <https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative/condition-specific-tools>

Education and Vocational Planning

Department of Education / IEP transition planning is required by Federal and NYS law to begin by age 15 years, with the aim of identifying the student's (and family's) long term goals for living, working and learning as an adult. The process should include interviewing the student (e.g. "what kind of job do you think you'd like to do when you graduate?" "What do you have to do to prepare for this kind of work?"), and input from the family. The planning should be based on age-appropriate transition assessments, set up measurable, achievable and relevant goals, and institute a coordinated set of transition activities including instruction, vocational trainings, related services (e.g. OT, PT, ST, counseling), community experiences and building daily living skills to reach those goals.

Graduation Options: High school graduation options include Regents diploma (academic diploma currently requiring passing 4 NYS Regents exams), Local diploma (for students with disabilities who pass Regents exams with the Safety Net), and non-diploma options (formerly "IEP diplomas") including Career Development and Occupational Studies (CDOS) – a certificate showing readiness for entry-level jobs), and Skills and Achievement Commencement Credential Certificate (SACCC) – for students with significant disabilities who take the NYS Alternate Assessment). Note that CDOS and SACCC are not actual high school diplomas and can't be used for application to college, military or trade schools.

ACCES-VR (Adult Career & Continuing Education Services – Vocational Rehabilitation) is a NYS Education Department-funded program for 14–23-year-olds to "assist individuals with disabilities to achieve and maintain employment and to support independent living" (<https://www.acces.nysed.gov/vr>). Starting at age 14, individuals with a documented disability can apply to ACCES-VR, and if eligible, will be supported in developing an "individualized plan for employment" (IPE), and receive services such as job counseling, job placement, vocational training, driver training and coaching, and supported employment. OPWDD's Supportive Employment Services (SEMP) may then follow with ongoing supported employment.

Transition Services and Post-Secondary Pathways

Advocates for Children of New York (AFC)

AFC's mission is to ensure a high quality education for New York students who face barriers to academic success, focusing on students from low-income backgrounds. AFC works simultaneously with students and their families, providing one-on-one guidance and advocacy, while also pressing for reforms at a system level that benefit all students. <https://advocatesforchildren.org/about/>

IncludeNYC (formerly Resources for Children with Special Needs) strives to promote positive futures and enhance quality of life for young people (birth to 26 years) with disabilities and their families – empowering them with the knowledge and skills to access and navigate systems and services, and with programs focused on transition. <https://includenyc.org>

AHRC New York City

AHRC advocates for people with intellectual, developmental and other disabilities to lead full and equitable lives. AHRC offers comprehensive services for individuals transitioning from school to adulthood, including day programs, employment training, and higher education pathways. Services also include individualized care plans and family support. <https://www.ahrcnyc.org/>. See AHRC Referral and Information Center: <https://www.ahrcnyc.org/ric/> or email Referrals@ahrcnyc.org

Higher Education Pathways: Melissa Riggio Higher Education Program: In partnership with CUNY Unlimited, providing post-secondary education for individuals with developmental disabilities. This program includes skill-building for independent living and career readiness. <https://www.ahrcnyc.org/services/school/college/>

Council on Quality and Leadership (CQL)

Focused on ensuring high-quality services for individuals with disabilities, with resources for service providers and families to improve outcomes. <https://www.c-q-l.org/>

New York State Education Department (NYSED)

Information on graduation pathways, special ed services and transition planning. <http://www.nysed.gov/>

Parent to Parent of NYS provides support, advocacy training, and resources for navigating transition planning and accessing services. <https://parenttoparentnys.org/>

Non-Academic Skill Development

In addition to academic goals, transition planning includes fostering non-academic skills critical for independent living and community integration:

- **Life Skills**
 - Personal care: hygiene, dressing, and self-care routines.
 - Financial management: budgeting, banking, and money handling.
 - Safety practices: community navigation, emergency response, and self-protection.
 - [Travel training](#): using public transportation and learning independent travel skills.
- **Social and Emotional Learning (SEL)**
 - Building self-awareness to recognize personal strengths and emotions.
 - Enhancing relationship skills to foster positive interactions.
 - Improving decision-making abilities for both daily tasks and long-term goals.
- **Vocational Skills**
 - Career exploration through internships and community programs.
 - Job readiness, including resume writing, interview preparation, and workplace etiquette.
 - Workplace interpersonal skills to adapt and collaborate effectively.

Community and Independent Living

Overview of OPWDD and Covered Services

The Office for People With Developmental Disabilities ([OPWDD](https://opwdd.ny.gov)) is a New York State agency that funds a wide range of disability programs and services. Supported through Medicaid, it requires individuals to secure Medicaid or a waiver to access these services. For more info: <https://opwdd.ny.gov/contact-us>.

An example of an OPWDD-supported program is Job Path Inc (www.jobpathnyc.org) which provides services to eligible individuals after they have transitioned from school, offering customized individual and group day programs, customized job development and job support, as well as support for independent living including supported housing.

The OPWDD process begins with the **Front Door** initiative, which includes calling 866-946-9733 and watching informational videos: <https://opwdd.ny.gov/front-door-overview>. Once enrolled, the individual is assigned a Care Coordination Organization ([CCO](https://opwdd.ny.gov/cco)) – in NYC these are Care Design NY, Advance Care Alliance, or Tri-County Care. The route to OPWDD services is through a Care Manager from the chosen CCO, who has a list of the provider agencies and services and will guide the person through the process of creating a [person-centered plan](https://opwdd.ny.gov/person-centered-plan) and accessing services.

OPWDD Front Door Information Sessions

These sessions are a gateway to accessing services through OPWDD. They include an overview of available programs, eligibility, and enrollment processes. Register: <https://opwdd.ny.gov/get-started/information-sessions>

Services Provided by OPWDD

Family Support Services (FSS):

- [Respite](#) Care
- Behavioral Support
- Social Skills Training
- Recreation Activities
- Specialized Summer Camps
- Parent and Sibling Support Groups

Home and Community-Based Services (HCBS): services typically provided in the community, but only available to those that are living independently or with family. Those living in [IRA's](#) (see below) are not eligible.

- **Day Habilitation ([Day-Hab](#)):** Day program services outside the home for adults with developmental disabilities – generally classroom-type settings, to help reach educational, recreational or long-term employment goals. Can provide higher level of support including Nursing, medication, [ADL's](#), modified diets. "Day Hab without Walls" is similar, but includes working in small groups in the community as well as on-site. <https://opwdd.ny.gov/types-services/day-services>
- **Community Habilitation ([Com-Hab](#)):** Supports for skills such as independent living, making friends, and participating in the community. Provides one-on-one service and moderate levels of support ([ADL's](#), modified diets), not medication. Available to individuals living with family or independently, with restrictions if in OPWDD-run homes

or [IRAs](#). Com-Hab Residential for individuals over 65 years or with high medical needs living in an IRA, with residential staff providing a higher level of support, including medication - 50% of services must be provided in the community.

Employment Supports - Vocational and Apprenticeship Programs: Opportunities for hands-on learning through internships, apprenticeships, and community-based skill-building programs to ease the transition to adult work environments.

- **[Site-based Prevocational Services](#)** – at an [OPWDD](#)-approved site, individual may earn wages, staff always on site, but minimal support. Meant to help develop skills and experience to lead to paid employment – tends to be repetitive type work ('piecework')
- **[Community-based Prevocational Services](#)** – individual may be placed as a volunteer in a community business or site, to more flexibly build job skills leading to paid employment. Program staff (employment specialist or 'job coach') act as liaison with the site, checking in periodically.
- **Employment Training Program (ETP)** – short-term internship program to prepare individual for a job, initially pays wages and provides job coaching support – these taper off when job becomes permanent, and employer takes over paying wages.
<https://opwdd.ny.gov/types-services/employment-training-and-supports>
- **Supportive Employment Services (SEMP)** – long-term support for a paid, competitive job in the community, typically following [ACCES-VR](#) – provides minimum job support services (periodic 'check-ins')
- **Enhanced Supported Employment (ESEMP):** Tailored for individuals needing intensive or long-term job support.

[Self-Direction](#): is an option that allows individuals and families to arrange and supervise services using an approved OPWDD budget.

- A "Self-Direction Support Broker" and "Fiscal Intermediary" are required to manage this program.
- Families pay for services and later submit for reimbursement.
- For more details: <https://opwdd.ny.gov/types-services/self-direction>

Independent Living and Housing Options

Independent Living supports (available through [OPWDD](#)):

- Housing cost subsidies through OPWDD's Individual Supports & Services ([ISS](#)) program – available for individuals with developmental disabilities who are living independently (or with their family, but with their name on the lease or mortgage)
- "[Paid neighbors](#)" – someone living nearby who is paid to be on call and assist as needed
- Self-direction (described above) can be used to cover furniture purchases, internet and phone service, and trash removal in support of independent living.
- Live-in-caregivers – paying an unrelated individual to live in the same home and provide support
- Environmental modifications (e.g., ramps, safety upgrades) to support independent living.

Supportive Apartments:

- Integrated Supported Housing (ISH) is typically based on a partnership between a housing developer and an OPWDD service provider. It supports the individual living in their own apartment or with a roommate, and staff who check in intermittently (several times/week) to support medication administration, medical appointments and transportation as well as financial decision making through a [Representative Payee](#) to help individuals maintain independence.

Family Care:

- Living with a certified and reimbursed family through OPWDD.

Group Homes:

- Includes **Individual Residential Alternatives (IRAs)**, paid through NYS Medicaid Waiver funds. In supervised IRA's, individuals receive room and board, live with a small group (typically 4-10, up to 14) and receive 24/7 staff support including Nursing, dietary, as well as financial decision-making support as needed.
- **Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID's)**, funded through Medicaid or Medicare, provide a more intensive level of Nursing and other care, for individuals with ID and more complex needs, including those with seizure disorders, mental health disorders, visual or hearing impairments

For more information about housing supports: <https://opwdd.ny.gov/types-services/housing>

Mental Health Considerations

Neurodiverse adolescents and young adults, including those with ASD, may face mental health challenges, particularly during the transition from adolescence to adulthood. Common conditions such as anxiety, depression, obsessive-compulsive disorder ([OCD](#)), and post-traumatic stress disorder (PTSD) are often heightened by the stress of navigating new environments and responsibilities. Recognizing and addressing these mental health needs is essential for supporting the overall well-being of these individuals.

Mental Health Problems in People with Learning Disabilities: Prevention, Assessment and Management: **NICE Guidelines:** <https://www.nice.org.uk/guidance/ng54/chapter/recommendations>

Understanding Psychiatric Comorbidities in ASD

Psychiatric conditions are common in individuals with ASD, with anxiety affecting up to 40% of youth. Depression, PTSD, and mood disorders are also frequently diagnosed. The transition to adulthood can intensify these challenges due to social pressures, disrupted routines, and increased self-awareness of differences from peers.

Barriers to Effective Care:

- Symptoms of mental health conditions are often mistaken for or overshadowed by ASD-related behaviors, delaying appropriate diagnosis and treatment.
- Individuals with limited verbal communication may struggle to express emotions like sadness, fear, or worry, making it harder for caregivers or clinicians to identify psychiatric concerns.
- A shortage of mental health professionals trained in both ASD and co-occurring conditions leaves families with limited access to specialized care.

Recommendations for Providers**Identify and Address Issues Early:**

Screening tools for psychiatric comorbidities, such as anxiety and depression, can be helpful, but many are not specifically designed for individuals with ASD. This limitation can result in misdiagnosis or overlooked conditions. Using these tools regularly, along with detailed family input can aid in identifying mental health concerns in this population. Commonly used tools include the Generalized Anxiety Disorder Scale (GAD-7) for anxiety, the Patient Health Questionnaire (PHQ-9) for depression, the Prodromal Questionnaire–Brief Version (PQ-B) for psychosis, and the Young Mania Rating Scale (YMRS) for mania.

Implement Tailored Interventions:

Interventions such as Cognitive Behavioral Therapy ([CBT](#)) can be effective in managing anxiety and depression but should be adapted to meet the individual’s sensory and communication needs. Therapy should be structured and focused on practical coping strategies. For individuals who may not be able to engage in CBT, behavioral supports can provide an alternative, focusing on modifying behaviors through structured routines and reinforcement. Unfortunately, many insurance plans do not cover behavioral therapy for adults, and it is often funded through waiver programs, which may limit access to these services.

Appropriate Use of Medications:

Medications such as selective serotonin reuptake inhibitors (SSRIs) can help manage anxiety and depression, with regular monitoring for side effects. For managing irritability and aggression, atypical [antipsychotics](#) like Risperidone or Aripiprazole are FDA-approved options.

Addressing Key Mental Health Concerns

- **Anxiety:** Transitions often exacerbate anxiety. Support strategies include gradual exposure to new situations, mindfulness techniques, and medication support if necessary.
- **Depression:** Social isolation, low self-esteem, and difficulty adjusting to life changes can contribute to depression in youth with ASD. A combination of therapy and, when needed, pharmacological treatment can significantly improve outcomes.
- **PTSD:** Many individuals with ASD experience trauma, such as bullying. [Trauma-informed care](#), which prioritizes safety and empowerment, is vital in these cases.

Special Considerations: Substance Use Disorder (SUD) and Suicide in Transition Aged Youth with ASD

Substance Use Disorders (SUD) and suicide are critical concerns for transition-age youth with ASD. These risks are often heightened by social isolation, co-occurring mental health conditions, and challenges with [self-advocacy](#). Youth with ASD may turn to substances as a coping mechanism for managing anxiety, stress, or social pressures, which can increase their vulnerability to developing SUD. However, the unique presentation of ASD-related behaviors can complicate early detection and diagnosis of substance use issues. Additionally, individuals with ASD experience higher rates of suicidal ideation and attempts compared to their neurotypical peers, often driven by untreated depression, bullying, or feelings of alienation.

Recommendations For Families:

Recognize the Warning Signs: Learn to identify behaviors that may indicate substance use or suicidal thoughts, such as withdrawal, sudden mood changes, increased secrecy, or changes in sleep or eating habits.

Create a Safe Space: Foster open communication with your child. Encourage them to share their feelings without fear of judgment and let them know help is available.

Seek Professional Support: Connect with mental health professionals experienced in working with ASD and co-occurring conditions. If you suspect substance use or suicidal ideation, seek immediate assistance through crisis services or mental health clinics.

Engage in Preventive Education: Teach your child about the dangers of substance use and provide tools to handle stress in healthy ways. Collaborate with schools or community programs that offer support and education tailored to youth with ASD.

Recommendations For Providers

Early Screening and Diagnosis: Incorporate routine screenings for SUD and suicidal ideation during visits, using tools like the CRAFFT Screening Interview for substance use and the Columbia-Suicide Severity Rating Scale (C-SSRS) for suicide risk.

Implement [Trauma-Informed Care](#): Ensure care approaches prioritize emotional safety and reduce stigma. Tailor interventions to address the unique communication and sensory needs of youth with ASD.

Coordinate Multidisciplinary Care: Work collaboratively with mental health professionals, social workers, and educators to provide comprehensive, individualized care plans that address both ASD and co-occurring risks.

Educate Families: Offer families guidance on recognizing signs of substance use and suicide risk and provide them with resources to support their child. Encourage active family involvement in prevention and intervention efforts.

Crisis Planning and Referrals: Develop clear crisis plans for at-risk youth and ensure timely referrals to specialized services, such as intensive outpatient programs or residential treatment centers when necessary.

Mental Health Resources

Crisis Support

- **Substance Abuse and Mental Health Services Administration (SAMHSA)**
A national resource for substance use. <https://www.samhsa.gov>
- **National Suicide Prevention Lifeline (988)**
24/7 crisis support for individuals experiencing suicidal thoughts or mental health crises.
<https://988lifeline.org>
- **Crisis Text Line: Text HOME to 741741**
Free, confidential support available 24/7 for youth and families in crisis.
<https://www.crisistextline.org/>
- **Autism Speaks: Safety and Crisis Resources**
Information on substance use, suicide prevention, and crisis planning for individuals with ASD.
<https://www.autismspeaks.org>

Additional Select Articles:

Cannabis and Autism: <https://www.autismspeaks.org/science-news/cannabis-and-autism>

Suicide Risk and Autism: <https://www.autismspeaks.org/expert-opinion/suicide-risk-autism>

Clinical Resources for Providers

- **Practice Parameter for the Assessment and Treatment of Psychiatric Disorders in Children and Adolescents with Intellectual Disability** [https://www.jaacap.org/article/S0890-8567\(19\)32223-3/pdf](https://www.jaacap.org/article/S0890-8567(19)32223-3/pdf)
- **Clinical Pearl Pocket Guide for Providers**
https://www.aacap.org/App_Themes/AACAP/Docs/member_resources/ASD-ID/Neurodevelopmental_Clinical_Pearls-pocket_guide.pdf

Parents' Medication Guides - Developed by AACAP and APA to support informed treatment decisions:

Main Resource Hub:

https://www.aacap.org/AACAP/Families_and_Youth/Family_Resources/Parents_Medication_Guides.aspx

Specific Guides:

- **ADHD:**
 - **English:**
https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/resources/med_guides/ADHD_Medication_Guide-web.pdf
 - **Spanish:**
https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/resources/med_guides/ADHD_Medication_Guide_Spanish-web.pdf
- **ADHD in Youth with ASD:**
https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/resources/med_guides/ADHDwithASD_Web.pdf

- **Anxiety Disorders:**
 - **English:**
https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/resources/med_guides/anxiety-parents-medication-guide.pdf
 - **Spanish:**
https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/resources/med_guides/anxiety-parents-medication-guide-spanish.pdf
- **Autism Spectrum Disorder:**
https://www.aacap.org/App_Themes/AACAP/Docs/resource_centers/autism/Autism_Spectrum_Disorder_Parents_Medication_Guide.pdf
- **Bipolar Disorder:**
https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/resources/med_guides/BipolarDisorderGuide_Web.pdf
- **Depression:**
https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/resources/med_guides/Depression_Guide-web.pdf
- **Impairing Emotional Outbursts:**
https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/resources/med_guides/Outbursts_Parents_Medication_Guide-web.pdf
- **Sleep Disorders:**
https://www.aacap.org/App_Themes/AACAP/Docs/families_and_youth/med_guides/SleepDisorders_Parents-Medication-Guide-web.pdf

Mental Health Resources for Individuals with Developmental Disabilities

- **Young Adult Institute (YAI)**
Offers mental health services specifically for individuals with intellectual and developmental disabilities, their partners, and caregivers.
<https://www.yai.org/clinical-services/mental-health>
- **JCCA Compass Program**
Provides mental health services for teens and young adults with disabilities.
<https://www.jccany.org/our-programs/jewish-programs/compass/>
 - **Additional Services:**
 - **Psychology Services:** <https://www.jccany.org/our-programs/behavioral-health-and-wellness/psychology-services/>
 - **Behavioral Health and Wellness:** <https://www.jccany.org/our-programs/behavioral-health-and-wellness/>
- **JCCA Health Home**
Offers mental health services for individuals not enrolled in OPWDD.
<https://www.jccany.org/our-programs/behavioral-health-and-wellness/health-homes/>

Mental Health Resources for Caregivers and Family Members

- **NYC Well**
Provides free, confidential counseling, mental health support, and referrals.
<https://nycwell.cityofnewyork.us/en/>
- **Weill Cornell: Mental Health Resources for Vulnerable Populations**
Offers free or low-cost mental health services for asylum seekers and other vulnerable individuals in NYC.
<https://humanrights.weill.cornell.edu/resources/mental-health-resources-nyc>
- **Child Mind Institute**
A non-profit organization providing mental health services to children.
<https://childmind.org/>
- **National Alliance on Mental Illness (NAMI)**
A mental health organization offering a variety of mental health resources.
<https://nami.org/>
- **On Our Sleeves**
Provides mental health resources for children.
<https://www.onoursleeves.org/>
- **New York Psychotherapy and Counseling Center (NYPCC)**
A non-profit community mental health organization offering services to their communities.
<https://nypcc.org/>

Cognitive Behavioral Therapy (CBT): Supporting Mental Health During Transition

Cognitive Behavioral Therapy (CBT) is an evidence-based approach widely used to address anxiety and mental health challenges in neurodiverse individuals, including those with ASD. Adapting CBT to meet the sensory, communication, and developmental needs of transition-age youth with ASD is essential for effective outcomes.

Key Features of CBT

CBT is structured around helping individuals understand the connections between their thoughts, feelings, and behaviors. It is:

- **Skills-Based:** Focused on teaching coping and problem-solving skills.
- **Present-Focused:** Centers on current challenges rather than past events.
- **Goal-Oriented and Structured:** Progresses through specific, measurable goals.

Application of CBT for Individuals with ASD:

CBT has shown significant promise in managing anxiety and social challenges in individuals with [high-functioning](#) ASD. However, it requires specific adaptations to address the unique needs of this population.

Common Treatment Targets:

Managing Anxiety: Helping individuals confront and reduce fears through exposure therapy.

Improving Social Communication: Building skills to enhance social interactions using role-play and visual aids.

Reducing Repetitive Behaviors: Distinguishing between anxiety-driven behaviors and ASD-specific tendencies: Addressing Cognitive Inflexibility: Reframing rigid thought patterns to promote adaptability.

Suggested Adaptations for CBT in ASD

Concrete, Visual Aids: Use visual schedules, social stories, and written instructions to clarify abstract concepts.

Parent Involvement: Train parents to reinforce skills at home and provide ongoing feedback on progress.

Simplified Steps: Break down tasks into manageable parts to reduce overwhelm.

Behavioral Rehearsal: Practice skills repeatedly to build confidence and fluency.

Practical Tips for Providers

Assessment: Use structured tools and multiple informants (e.g., parents, teachers) to identify anxiety and other treatment targets. Differentiate anxiety from core ASD features, such as insistence on sameness.

Individualized Interventions: Integrate sensory needs and communication preferences into therapy. Use clear and literal language to avoid misinterpretation.

Engage the Family: Involve family members in skill reinforcement. Provide psychoeducation to help caregivers identify signs of anxiety and promote coping skills.

Resources for Evidence-Based CBT Programs:

Adaptations to traditional CBT can significantly improve its effectiveness for individuals with ASD, particularly those with co-occurring anxiety (Sze & Wood, 2008). These modifications include:

- **Use of Concrete and Visual Supports:** Visual aids, written schedules, and clear, concrete language are essential to help individuals with ASD better understand abstract CBT concepts like cognitive distortions or coping strategies.
- **Structured and Predictable Format:** Maintaining a consistent session structure and providing step-by-step guidance reduce anxiety related to unpredictability, which is common in ASD.
- **Integration of Special Interests:** Incorporating an individual's restricted interests into therapy activities can enhance engagement and motivation during tasks like cognitive restructuring or exposure exercises.
- **Focus on Emotional Regulation:** Simplified tools, such as emotion charts or labeling exercises, are helpful in connecting thoughts, emotions, and behaviors. This approach supports the development of self-regulation skills.
- **Targeting Social Skills Deficits:** Role-playing, social scripts, and perspective-taking exercises address challenges in social interactions, which are often linked to anxiety in individuals with ASD.

- **Caregiver Involvement:** Including caregivers in therapy by training them to reinforce techniques at home—particularly for exposure exercises—ensures consistency and generalization of skills.

See link for full article:

http://journals.cambridge.org/abstract_S1352465808004384

The following manualized CBT programs have been tailored for individuals with ASD:

Coping Cat: Teaches relaxation techniques and exposure therapy. <https://www.copingcatparents.com/>

Facing Your Fears: Offers individualized approaches to reduce anxiety through graduated exposure.

<https://pmc.ncbi.nlm.nih.gov/articles/PMC3471403/>

Exploring Feelings: A program by Dr. Tony Attwood, addressing emotional regulation and anxiety management. <https://autismawarenesscentre.com/shop/behaviour/anxiety/exploring-feelings-cognitive-behaviour-therapy-to-manage-anxiety/>

Behavioral Interventions for Anxiety in Children: Combines anxiety management with social skills training.

Recommendations for Families:

Encourage Participation: Involve your child in discussing therapy goals and practicing skills.

Support Skill Application: Reinforce CBT strategies at home and in everyday situations.

Communicate with Providers: Share observations and concerns with the therapist to tailor interventions effectively.

Sexuality and Relationships

Sexual Health Education for Transitioned Aged Neurodiverse Youth

Adolescents with ASD often lack adequate sexual health education, which can hinder their understanding of relationships and sexuality. They may struggle with abstract concepts like consent and privacy, have difficulty with social cues, and nearly half have limited access to formal education on these topics. This gap can result in behaviors such as public masturbation or boundary-crossing in romantic situations. Additionally, difficulties in recognizing unsafe situations or communicating about them increase their risk of abuse and exploitation. Comprehensive, ASD-specific sexual health education that includes lessons on personal safety and boundaries is essential to address these challenges.

Strategies for Sexual Health Education:

Teach Social Norms and Consent: Use visual aids, social stories, and behavioral mapping to explain boundaries and appropriate interactions.

Address Individual Needs: Adapt education to developmental levels, sensory sensitivities, and cognitive abilities.

Involve Families: Professionals should incorporate parents with the skills to reinforce education at home and guide discussions on sensitive topics.

Incorporate Applied Behavior Analysis (ABA): Systematically reinforce appropriate behaviors while discouraging problematic ones.

Resources for Families and Self-Advocates:

Healthy Bodies Toolkit: A comprehensive guide for teaching puberty and sexual health to youth with ASD. <https://vkc.vumc.org/healthybodies/>

A Sex-Ed Guide for Self Advocates: <https://researchautism.org/self-advocates/sex-ed-for-self-advocates/>

Relationship Building & Sexual Awareness for Kids with Autism: S.T.A.R.S 2 Authors: SK Webster & S Heighway (available on Amazon)

Gender Identity and ASD

Exploration and affirmation of gender identity are important components of self-discovery during adolescence. Research shows a notable overlap between ASD and gender dysphoria (GD), necessitating targeted and affirming care for youth who experience it. They often face challenges such as rigid thinking, which can make it difficult to explore and express their gender identity, and sensory sensitivities, which may impact their ability to engage comfortably with gender-affirming treatments.

Practical Tips for Families and Self-Advocates:

Start Early and Be Direct: Initiate conversations about sexuality, relationships, and gender identity early, using clear and straightforward language.

Teach Healthy Relationship Skills: Help youth understand different types of relationships and practice social interactions through role-playing and visual aids.

Reinforce Personal Safety: Educate about privacy, consent, and boundaries to protect against exploitation and misunderstandings.

Recognize the link to Mental Health: Highlight how healthy relationships and affirmed gender identity contribute to emotional well-being.

For Providers: Providing Affirming Care:

Normalize Discussions: Incorporate sexuality and gender identity into routine care to provide a safe space for open dialogue.

Provide Tailored Education: Use tools like social stories and visual aids to address unique challenges in understanding abstract concepts.

Prevent Exploitation: Teach youth and families to recognize unsafe situations and establish protocols for addressing concerns.

Collaborate with Families and Educators: Deliver consistent and developmentally appropriate education that adapts as the individual grows.

Resources for Providers:

Initial Clinical Guidelines for Co-Occurring ASD and Gender Dysphoria: Guidance on creating affirming care plans for these youth. <https://pubmed.ncbi.nlm.nih.gov/27775428/>

Guardianship, Alternatives & Legal and Financial Support

Transitioning into adulthood brings up issues of [guardianship](#) as well as unique legal and financial challenges for individuals with neurodevelopmental disabilities and their families. Below are useful resources and websites to help navigate these challenges.

Guardianship Options: When individuals with disabilities reach adulthood, they are legally expected to make medical, financial, and legal decisions independently. Families may need to explore custody or guardianship arrangements to ensure continuity of care and decision-making support.

17A Guardianship

Designed for individuals with developmental or intellectual disabilities. Cost-effective and straightforward to pursue in New York State without requiring legal representation. However 17A guardianship is highly restrictive, removing an individual's rights to self-determination. It is often not the best option for those capable of partial independence.

<https://nycourts.gov/courthelp/diy/guardianship17A.shtml>

Article 81 Guardianship

Offers a more flexible alternative, granting specific rights to the individual while appointing a guardian for necessary decisions. <https://nycourts.gov/courthelp/Guardianship/AIP.shtml>

Guardianship Alternatives

Families are encouraged to explore less restrictive options to support autonomy while safeguarding essential decisions:

- **[Supported Decision-Making \(SDM\)](#):** A voluntary agreement allowing individuals to collaborate with trusted supporters to make decisions while retaining their legal rights. Facilitators guide the creation of Supported Decision-Making Agreements (SDMA). <https://www.sdmny.org>
- **[Representative Payee](#):** A representative is appointed to manage Social Security benefits and finances on behalf of the individual.
- **HIPAA Release and Healthcare Proxy:** Enable family members to access medical information and make health-related decisions when necessary.

Families should weigh all options carefully, balancing the individual's need for independence with their ability to navigate adulthood safely. By understanding these systems, parents and caregivers can make informed choices to best support their loved ones during this transition.

Legal Assistance Groups

Families navigating legal and financial complexities can benefit from assistance offered by specialized organizations:

The Legal Aid Society - Defending the rights of New Yorkers, the Legal Aid Society supports individuals with disabilities in obtaining and maintaining their entitled benefits. <https://legalaidnyc.org>

The New York Legal Assistance Group (NYLAG) - NYLAG provides free civil legal services for individuals and families in crisis, offering guidance on issues like special education legalities and disability rights.

<https://nylag.org>

Transportation and Accessibility

Accessible transportation services are essential for individuals with disabilities to navigate their communities, attend school, and participate in various activities. The following programs offer tailored support for individuals with special needs:

Metropolitan Transportation Authority (MTA) Access-A-Ride Paratransit Program

A door-to-door transportation service designed for individuals with disabilities who are unable to use public transit. <https://new.mta.info/accessibility/paratransit>

MTA Reduced Fare Program for People with Disabilities

This program allows eligible customers to pay half the transportation fare, making transit more affordable for individuals with disabilities. <https://new.mta.info/sites/default/files/2018-07/disabled.pdf>

NYC DOE School Bus Service for Students with Disabilities (SWD)

The New York City Department of Education provides door-to-door transportation for students with disabilities, ensuring they can travel safely to and from school.

<https://www.schools.nyc.gov/school-life/transportation/bus-eligibility>

Culture, Leisure, and Recreation

Engaging in cultural and recreational activities is essential for fostering social inclusion and enriching the lives of individuals with disabilities. New York City offers a range of accessible programs and resources for neurodiverse individuals and their families:

Subway Sleuths - New York Transit Museum

A 10-week afterschool program designed for students with autism, offering interactive learning opportunities. <https://www.nytransitmuseum.org/learn/subwaysleuths/>

New York City Ballet Access Program

Provides individuals with varying abilities the opportunity to experience the art of ballet through specialized programs. <https://www.nycballet.com/educate/access-programs>

Lincoln Center Accessibility Programs

Offers performances and events tailored to audiences with autism and other developmental disabilities. <https://www.lincolncenter.org/series/accessibility-at-lincoln-center>

MoMA Accessibility Program

Hosts art workshops for individuals with intellectual disabilities and their families.

<https://www.moma.org/visit/accessibility/>

Whitney Museum of American Art Accessibility

Welcomes all visitors, disabled and non-disabled, to explore and appreciate American art.

<https://whitney.org/education/access>

Intrepid Museum Access Program

Monthly programs designed for individuals with developmental disabilities and their families, focusing on interactive experiences. <https://www.intrepidmuseum.org/education/access-family-programs>

New York Hall of Science Accessibility Initiative

Provides STEM learning opportunities tailored to individuals with developmental disabilities.

<https://nysci.org/autism-access-initiative>

Queens Museum Art Access Programs

Offers assistive services, including tours, ASL interpreters, large print materials, and art programs for children and adults with disabilities.

<https://queensmuseum.org/event/art-access-museum-explorers-for-children-with-disabilities/>

American Museum of Natural History Accessibility Services

Provides assistive services such as tours, ASL interpreters, and large print resources. Service animals are welcome. <https://www.amnh.org/plan-your-visit/accessibility-language-assistance>

Culture Pass

A collaborative program with NYC libraries, allowing library cardholders to reserve one free day pass per institution annually. <https://www.culturepass.nyc>

IDNYC

A free government-issued photo ID for individuals 10 years and older residing in NYC, offering benefits such as museum memberships and access to city services.

<https://www.nyc.gov/site/idnyc/benefits/museums-and-cultural-institutions.page>

Summer Camps

Summer camps provide enriching opportunities for neurodiverse youth, offering tailored support to ensure an inclusive and enjoyable experience. Below is a list of resources for families seeking specialized summer programs:

DOE NYC Summer Rising A free summer program for students in grades K-8, including those with disabilities. <https://www.schools.nyc.gov/enrollment/summer/grades-k-8>

Hebrew Educational Society (HES) Summer Camp Offers summer camps with specialized support for children with disabilities. <https://www.thehes.org/summer-camp/>

Mommy Poppins Provides information about specialized summer camps for children with disabilities, including those with autism, ADHD, and sensory needs. <https://mommypoppins.com/newyorkcitykids/nyc-summer-camps-autism-special-needs-aspergers-adhd-sensory>

New York Family A resource for finding summer camps tailored to children with special needs. <https://www.newyorkfamily.com/camps-for-kids-with-special-needs/>

Very Special Camps A directory of summer camps and programs specifically designed for individuals with special needs. <https://www.verspecialcamps.com/>

American Camp Association of NY and NJ Dedicated to preserving and enhancing the quality of the summer camp experience for all children, including those with special needs. <https://www.acanynj.org/>

Resource Link Compilation:

Healthcare Transition

1. Got Transition: <https://www.gottransition.org>
2. Autism Speaks Healthcare Transition Toolkit: <https://www.autismspeaks.org/tool-kit>
3. National Alliance to Advance Adolescent Health: <https://www.thenationalalliance.org>
4. Mayo Clinic Autism and Digestive Symptoms: <https://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/expert-answers/autism-and-digestive-symptoms/faq-20322778>

Education and Vocational Planning

5. ACCES-VR: <https://www.acces.nysed.gov/vr>
6. AHRC NYC Melissa Riggio Program: <https://www.ahrcnyc.org/services/school/college/>

Community and Independent Living

7. OPWDD Services: <https://opwdd.ny.gov/contact-us>
8. OPWDD Front Door Overview: <https://opwdd.ny.gov/front-door-overview>
9. Self-Direction Program Details: <https://opwdd.ny.gov/front-door-overview>

Mental Health

10. SAMHSA: <https://www.samhsa.gov>
11. National Suicide Prevention Lifeline (988): <https://988lifeline.org>
12. Crisis Text Line: <https://www.crisistextline.org/>
13. Autism Speaks Safety and Crisis Resources: <https://www.autismspeaks.org>
14. Autism Speaks: Cannabis and Autism: <https://www.autismspeaks.org/science-news/cannabis-and-autism>
15. Autism Speaks: Suicide Risk and Autism: <https://www.autismspeaks.org/expert-opinion/suicide-risk-autism>
16. Child Mind Institute: <https://childmind.org>
17. Young Adult Institute (YAI): <https://www.yai.org/clinical-services/mental-health>
18. NYC Well: <https://nycwell.cityofnewyork.us/en/>
19. Weill Cornell Mental Health Resources: <https://humanrights.weill.cornell.edu/resources/mental-health-resources-nyc>
20. National Alliance on Mental Illness (NAMI): <https://nami.org>
21. On Our Sleeves: <https://www.onoursleeves.org>
22. New York Psychotherapy and Counseling Center (NYPCC): <https://nypcc.org/>

CBT Resources

23. Coping Cat: <https://www.copingcatparents.com/>
24. Facing Your Fears: <https://pmc.ncbi.nlm.nih.gov/articles/PMC3471403/>
25. Exploring Feelings by Dr. Tony Attwood: <https://autismawarenesscentre.com/shop/behaviour/anxiety/exploring-feelings-cognitive-behaviour-therapy-to-manage-anxiety/>

Sexuality and Relationships

26. Healthy Bodies Toolkit: <https://vkc.vumc.org/healthybodies/>
27. Initial Guidelines for ASD and Gender Dysphoria: <https://pubmed.ncbi.nlm.nih.gov/27775428/>

Legal and Financial Support

28. Legal Aid Society: <https://legalaidsnyc.org>
29. Supported Decision-Making NY: <https://www.sdmny.org>
30. 17A Guardianship Information: <https://nycourts.gov/courthelp/diy/guardianship17A.shtml>

31. Article 81 Guardianship Details: <https://nycourts.gov/courthelp/Guardianship/AIP.shtml>

Transportation

32. MTA Access-A-Ride: <https://new.mta.info/accessibility/paratransit>
33. MTA Reduced Fare Program: <https://new.mta.info/sites/default/files/2018-07/disabled.pdf>

Culture and Recreation

34. Subway Sleuths Program: <https://www.nytransitmuseum.org/learn/subwaysleuths/>
35. NYC Ballet Access Program: <https://www.nycballet.com/educate/access-programs>
36. Lincoln Center Accessibility Programs: <https://www.lincolncenter.org/series/accessibility-at-lincoln-center>
37. MoMA Accessibility Program: <https://www.moma.org/visit/accessibility/>
38. Whitney Museum Accessibility: <https://whitney.org/education/access>
39. Intrepid Museum Access Programs: <https://www.intrepidmuseum.org/education/access-family-programs>
40. Queens Museum Art Access Programs: <https://queensmuseum.org/event/art-access-museum-explorers-for-children-with-disabilities/>
41. American Museum of Natural History Accessibility: <https://www.amnh.org/plan-your-visit/accessibility-language-assistance>
42. Culture Pass NYC: <https://www.culturepass.nyc>

Summer Camps

43. DOE NYC Summer Rising: <https://www.schools.nyc.gov/enrollment/summer/grades-k-8>
44. Mommy Poppins Summer Camp Guide: <https://mommypoppins.com/newyorkcitykids/nyc-summer-camps-autism-special-needs-aspergers-adhd-sensory>
45. Very Special Camps: <https://www.verypecialcamps.com/>

Post-test questions for Transition / Neurodiversity conference

For answers and explanations to questions 1-7, take the MOC post-test through your conference link.

Questions 8 – 15 have answers and explanations below.

1. You are a primary care provider evaluating a 26-year-old woman with ASD and intellectual disability who is non-verbal for increased irritability, aggressive behavior, and decreased appetite for 3 days. She can dress and use the toilet on her own. She does not have a fever, vomiting, or upper respiratory symptoms. What are important considerations when evaluating this concern?
 - a. Consider starting or increasing [antipsychotics](#) to treat aggressive behavior.
 - b. Ask the caregiver about observed bowel habits and consider an abdominal x-ray to evaluate for constipation.
 - c. Refer to a gastroenterologist and a dentist for an evaluation.
 - d. Recommend bland diet and slowly advancing as tolerated.

2. Occupational therapists working with neurodiverse individuals in preparation for aging out of the school system may focus on which of the following:
 - a. Activities of Daily Living ([ADLs](#))
 - b. Social/recreational participation
 - c. Job preparation
 - d. Community mobility
 - e. An OT may deal with all of the above
 - f. a, b, and d

3. You are a social worker seeing a family of a 19 year old with autism and mild intellectual disability. She plans to seek vocational training after high school and hopes to live on her own when she reaches adulthood. The family is concerned about her ability to make financial and health care decisions, and whether they'll be able to be involved in her medical care once she reaches 21 years. They ask you about [guardianship](#) options. Which of the following options would you recommend?
 - a. 17A petition (in NYS) – for full guardianship
 - b. Article 81 guardianship (in NYS) – a less restrictive form with more rights for the individual
 - c. A [Supported Decision-Making](#) Agreement combined with HIPAA release and Healthcare proxy
 - d. Assignment of a [Representative Payee](#)
 - e. You explain the importance of respecting her individual rights and self-determination as she becomes an adult, and that *no* guardianship arrangement is needed

4. You are a psychiatrist asked to see an 18 year old with a history of autism who says he is hearing voices, is talking in disjointed fashion, moving his hands about rapidly, and according to his teachers and family is behaving in bizarre ways. Your colleagues suggest that he is having a psychotic break and want to start [antipsychotics](#). What do you do?
 - a. Reassure everyone that his clinical picture is consistent with his autism and no action is needed
 - b. Note that psychotic episodes can co-occur in autism, and promptly begin a course of first-line antipsychotics together with wrap-around services
 - c. Take a developmental history to ascertain whether his current picture is a significant departure from his baseline and determine a treatment plan accordingly
 - d. Nothing right now – gather corroborative information

5. Which of the following early factors may shape the development of ASD?
 - a. Rare genetic mutations
 - b. Common genetic mutations
 - c. Epigenetic processes
 - d. Prenatal exposures
 - e. Postnatal exposures
 - f. All of the above

6. Diagnosing children in the Early Intervention period is important because otherwise they will likely:
 - a. Not receive the diagnosis of ASD in preschool and elementary school
 - b. Not access the Department of Education autism specialized services
 - c. Not be eligible for insurance-based Applied Behavior Analytic (ABA) services
 - d. Have poorer long-term trajectories and transition-to-adulthood [outcomes](#)
 - e. All of the above

7. Which mental health conditions are most commonly found co-occurring with ASD during the transition to adulthood?
 - a. Schizophrenia and bipolar disorder
 - b. Anxiety and depression
 - c. ADHD and psychosis
 - d. PTSD and [OCD](#)
 - e. All of the above

8. A 19-year-old man with ASD and moderate intellectual disability returns for follow up after starting a selective serotonin reuptake inhibitor and low-dose risperidone for anxiety and associated self-harm behavior. His mother reports that he is markedly calmer, sleeping better, and has rare outbursts. However, he has gained 10 pounds in the last 4 months. What do you recommend as next steps?
 - a. Stop the risperidone as it is causing weight gain.
 - b. Continue current medications but recommend diet changes and regular exercise.
 - c. Start metformin to offset the metabolic syndrome side effects of the risperidone.
 - d. Start a glucagon-like peptide 1 agonist to help with weight loss.

(Answer c): While antipsychotics are helpful in reducing aberrant and/or aggressive behavior in ASD, weight gain and metabolic changes are common. Metformin has been shown to promote significant decrease in weight and BMI percentiles in children and adolescents with ASD who are prescribed antipsychotic medications. As this patient has had a good response to risperidone, stopping may result in return of aberrant behaviors. While regular diet and exercise are recommended for everyone, implementation maybe challenging and may not lead to significant weight loss for this patient. While glucagon-like peptide-1 agonists are effective to help with weight loss in individuals prescribed antipsychotics, more studies are needed before recommending for routine use.

Sources: DeVane CL, Charles JM, Abramson RK, Williams JE, Carpenter LA, Raven S, Gwynette F, Stuck CA, Geesey ME, Bradley C, Donovan JL, Hall AG, Sherk ST, Powers NR, Spratt E, Kinsman A, Kruesi MJ, Bragg JE Jr. Pharmacotherapy of Autism Spectrum Disorder: Results from the Randomized BAART Clinical Trial. *Pharmacotherapy*. 2019 Jun;39(6):626-635. doi: 10.1002/phar.2271. Epub 2019 May 29. PMID: 31063671; PMCID: PMC6555676.

Handen BL, Anagnostou E, Aman MG, Sanders KB, Chan J, Hollway JA, Brian J, Arnold LE, Capano L, Williams C, Hellings JA, Butter E, Mankad D, Tumuluru R, Kettel J, Newsom CR, Peleg N,

Odrobina D, McAuliffe-Bellin S, Marler S, Wong T, Wagner A, Hadjiyannakis S, Macklin EA, Veenstra-VanderWeele J. A Randomized, Placebo-Controlled Trial of Metformin for the Treatment of Overweight Induced by Antipsychotic Medication in Young People with Autism Spectrum Disorder: Open-Label Extension. *J Am Acad Child Adolesc Psychiatry*. 2017 Oct;56(10):849-856.e6. doi: 10.1016/j.jaac.2017.07.790. Epub 2017 Aug 19. PMID: 28942807. Siskind D, Hahn M, Correll CU, Fink-Jensen A, Russell AW, Bak N, Broberg BV, Larsen J, Ishøy PL, Vilsbøll T, Knop FK, Kisely S, Ebdrup BH. Glucagon-like peptide-1 receptor agonists for antipsychotic-associated cardio-metabolic risk factors: A systematic review and individual participant data meta-analysis. *Diabetes Obes Metab*. 2019 Feb;21(2):293-302. doi: 10.1111/dom.13522. Epub 2018 Oct 7. PMID: 30187620.

9. Under the 2004 Individuals with Disabilities Education Act (IDEA), transition planning and services should address which of the following:

- a. Postsecondary education
- b. Vocational training
- c. Supported employment
- d. Community participation
- e. Sexuality education
- f. All of the above
- g. a – d

(Answer g): Transition planning components mandated under IDEA include postsecondary education (i.e. after high school), vocational training, employment and community participation and, as appropriate, independent living but do *not* include sexuality education or [guardianship](#).

Source: Statfeld, J., Fine, C., (2022) Transition Planning Under IDEA for Students with Disabilities. Education Law Center. chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://files.eric.ed.gov/fulltext/ED624569.pdf

10. You are the primary care provider for a 23 year old male with high-needs autism who is participating in a [Com Hab](#) program during the day and living at home with his parents and 3 siblings. He has a history of intermittent outbursts managed for many years with a low dosage regimen of Aripiprazole. His family brings him in to see you, reporting markedly increased agitated behavior over the past 3 weeks including lashing out at those around him. Your first step is to:

- a. Refer him immediately to the Psych ER
- b. Moderately increase his Aripiprazole dosage
- c. Explore recent changes in his environment
- d. Explore medical reasons for his increase agitation
- e. Refer him to a mental health specialist
- f. All of the above
- g. c and d

(Answer g): The correct approach is to explore recent changes in his environment and investigate possible medical reasons for his increased agitation. In individuals with high-needs autism, behavioral changes often stem from external or medical factors. Environmental shifts, such as changes in routine, caregivers, or sensory stimuli, may cause significant distress resulting in aggressive behavior. Similarly, medical issues like infections, pain, or gastrointestinal problems are common triggers for agitation in this population and may not be recognized due to communication challenges. It's vital to address these underlying causes before considering medication adjustments or psychiatric referrals.

Source: Edelson S. M. (2022). Understanding Challenging Behaviors in Autism Spectrum Disorder: A Multi-Component, Interdisciplinary Model. *Journal of personalized medicine*, 12(7), 1127. <https://doi.org/10.3390/jpm12071127>

11. Your living situation impacts which Home- and Community-Based Services ([HCBS](#)) waiver services you can access. True or False?

(Answer – True): Certain HCBS waiver services are contingent upon an individual's living situation, for example, Community Habilitation ([Com-Hab](#)) and Self direction are only available for those not living in a certified setting.

Source: <https://omh.ny.gov/omhweb/bho/hcbs.html>

12. New York State's Office of People with Developmental Disorders ([OPWDD](#)) supports and services are only available to those living in a certified setting. True or False?

(Answer – False): Individuals who are OPWDD eligible can access services regardless of where they reside.

Source: <https://opwdd.ny.gov/eligibility>

13. What percentage of adults with ASD experience at least one lifetime psychiatric disorder?

- a. 21%
- b. 48%
- c. 57%
- d. 79%
- e. 100%

(Answer d): Studies indicate that 79% of adults with ASD meet criteria for at least one psychiatric disorder over their lifetime, with the most common co-occurring disorders include mood and anxiety disorder. This high prevalence underscores the importance and need for psychiatric screening and intervention by providers when working with ASD individuals.

Source: Lever, A. G., & Geurts, H. M. (2016). Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(6), 1916–1930. <https://doi.org/10.1007/s10803-016-2722-8>

14. Once the individual has obtained gainful employment, there are no supports and services available. True or False?

(Answer – False)- supportive employment is a service that supports individuals who have gainful employment in the community.

Source: <https://omh.ny.gov/omhweb/adults/supported-employment-services/>

15. Which factors create significant challenges in ensuring smooth transitions for adolescents with ASD and co-occurring mental health conditions?

- a. Resistance from families to transition planning and limited pediatric expertise in adult care
- b. Differences in service delivery models between pediatric and adult care, and a lack of care coordination
- c. Financial constraints faced by families and the discontinuation of mental health services during transition
- d. Inadequate educational services and insufficient support from mental health providers

(Answer b): Culnane et al. (2020) emphasized that disconnect and fragmentation between pediatric and adult services creates significant obstacles during the transition process for adolescents with ASD and co-occurring mental health disorders. A major challenge is that pediatric and adult healthcare systems operate under different models, often leading to poor communication and inconsistent care coordination. The findings highlight the importance of structured transition planning and care coordination to reduce these disruptions such as the “Fearless, Tearless Transitions.”

Source: Culnane, E., Loftus, H., Efron, D., et al. (2020). Development of the Fearless, Tearless Transition model of care for adolescents with an intellectual disability and/or autism spectrum disorder with mental health comorbidities. *Developmental Medicine & Child Neurology*, 63(5), 560–565. <https://doi.org/10.1111/dmcn.14766>

GLOSSARY

A1C (hemoglobin A1C) - a blood test that measures average blood sugar levels over the past 2-3 months. It is commonly used to diagnose and monitor diabetes and prediabetes.

AAC (Augmentative and Alternative Communication) - tools and strategies, such as communication boards or speech-generating devices, used to support individuals with limited verbal communication abilities.

ABA – Applied Behavioral Analysis, is a health and educational intervention based on learning theory and operant conditioning to shape socially important behaviors. ABA is applicable for a wide range of conditions but is best known as a treatment for autism spectrum. While controversial in the disability community (in part because it is often implemented by improperly qualified providers) it remains the treatment for autism with the strongest evidence base.

Ableism – “the discrimination of and social prejudice against people with disabilities based on the belief that typical abilities are superior. At its heart, ableism is rooted in the assumption that disabled people require ‘fixing’ and defines people by their disability. Like racism and sexism, ableism classifies entire groups of people as ‘less than’, and includes harmful stereotypes, misconceptions, and generalizations of people with disabilities.” – Ashley Eisenmenger,

<https://www.accessliving.org/newsroom/blog/ableism-101/>

Acceptance-Commitment Therapy (ACT) - is a type of psychotherapy that helps individuals move beyond negative thoughts and feelings and move forward to commit to make changes in their lives.

<https://my.clevelandclinic.org/health/treatments/acceptance-and-commitment-therapy-act-therapy>.

ACCES-VR (Adult Career & Continuing Education Services – Vocational Rehabilitation) – is a NYS Education Department program for eligible 14-23 year olds with disabilities to support vocational training, job placement and early job support <https://www.acces.nysed.gov/vr> . See also SEMP.

Adaptive CBT - a version of Cognitive Behavioral Therapy tailored to the sensory, communication, and cognitive needs of individuals with ASD.

Adaptive Functioning – an individual’s ability to negotiate everyday life and achieve a level of independence. It includes communication, activities of daily living, socialization and self-care. Common instruments to measure adaptive functioning include the Vineland-3, DABS and the ABAS-II.

ADL’s (Activities of Daily Living) – basic tasks of everyday living such as eating with utensils, showering, dressing, and toileting (see also Instrumental ADL’s).

Antipsychotic - a type of medication used to manage symptoms of conditions such as schizophrenia, bipolar disorder, and agitation in autism. Examples include Risperidone and Aripiprazole.

Article 16 Clinics – in NYS, health clinics run by OPWDD that focus on providing interdisciplinary habilitative services for individuals with IDD, with less emphasis on comprehensive medical care (e.g they do not provide gynecological care) - <https://opwdd.ny.gov/providers/article-16-clinics>

ASDCS – certified Autism Spectrum Disorder Clinical Specialist – an on-line training certification course on strengths-based therapies, for psychologists, occupational therapists, social workers, licensed creating arts therapists and other practitioners working with autism spectrum clients.

ASD Nest – in NYC, one of two (along with Horizon) autism-focused classroom settings within the community school system. ASD Nest are designed for students with low-needs autism who are at or above grade level academically. ASD Nest uses an inclusion approach in which 5-6 eligible children with ASD are placed in an integrated classroom with grade level curriculum with both a general education teacher and a special education teacher who are trained to work with autism spectrum students, and with specialized supports such as Social Development Intervention (social skills training).

<https://www.schools.nyc.gov/learning/special-education/school-settings/specialized-programs>.

Behavioral Inflexibility - a characteristic of ASD marked by difficulty adapting to changes in routines or expectations, which can lead to distress or challenging behaviors.

Behavioral phenotype – the characteristic behavioral, cognitive, personality and psychiatric pattern that typifies a genetic syndrome.

CAS (Coordinated Assessment System) – in NYS, OPWDD's assessment process of strengths, needs and interests – required every 2 years, to request HCBS Waiver services.

CCO (Case Coordination Organization) – in NYS, the organizations that provide required care coordination management for individuals with developmental disabilities enrolled in OPWDD – developing a personalized Life Plan, and coordinating medical, dental, behavioral, social and community-based OPWDD services. There are 7 CCO's in NYS, with 3 which cover NYC: TriCounty Care, Care Design, and Advance Care Alliance. <https://includenyc.org/help-center/resources/care-coordination-organization/>

CDOS (Career Development and Occupational Studies) diploma – a non-academic alternative to a high-school diploma - a certificate showing readiness for entry-level jobs.

Cognitive Behavioral Therapy (CBT) - a structured, evidence-based therapy that helps individuals identify and change negative thought patterns to improve emotional and behavioral outcomes. It can be adapted for individuals with ASD.

Com-Hab (Community Habilitation) – OPWDD program supports skills such as independent living, making friends, and participating in the community. Available to individuals living with family or independently but not in OPWDD-run homes or IRAs.

Com-Hab R (Community Habilitation – Residential) – OPWDD program for individuals over 65 years or with high medical needs living in an IRA, with residential staff providing a higher level of support, including medication - 50% of services must be provided in the community.

Community-based prevocational services – program places individuals, often as volunteers, in a community business or site, program staff act as liaison with the site, checking in periodically (See also "Site-based Prevocational Services")

Co-morbidity – the simultaneous presence in an individual of a medical, psychiatric or developmental condition with another condition or diagnosis.

Co-Occurring Psychiatric Issues - mental health conditions that occur alongside a primary diagnosis, such as ASD. Common co-occurring psychiatric issues include anxiety, depression, obsessive-compulsive disorder (OCD), and attention-deficit/hyperactivity disorder (ADHD). These conditions may complicate diagnosis and treatment, requiring a comprehensive and individualized approach to care.

Day Hab (Day Habilitation) – [OPWDD](#) day program services outside the home – generally classroom-type settings, to help reach educational, recreational or long-term employment goals. Can provide higher level of support including Nursing, medication, [ADL's](#), modified diets. "Day Hab without Walls" is similar, but includes working in small groups in the community as well as on-site.

Diagnostic Overshadowing – a medical bias in which a patient's symptoms are attributed to an existing diagnosis rather than to possible other causes or co-morbidities, e.g. when a non-verbal autistic woman appears agitated and touches herself, and it is simply written off as "her autistic behavior" rather than evaluating other possible causes such as a yeast infection.

DM-ID-2 (Diagnostic Manual – Intellectual Disabilities 2nd ed) – based on the DSM-5 standard manual of psychiatric / neurodevelopmental diagnoses, but specially designed to assess, interpret symptoms and diagnose mental health conditions co-occurring with intellectual disability - <https://thenadd.org/products/dm-id-2/>

Dyadic unit – a pair of individuals interacting with each other, especially a parent and child, or a therapist and client – focusing on how they influence and respond to each other as a pair.

Employment Training Program – NYS short-term [OPWDD](#) internship program to prepare individual for a job, initially pays wages and provides job coaching support which taper off as job becomes permanent.

Epilepsy - a neurological condition characterized by recurrent seizures caused by abnormal electrical activity in the brain. Epilepsy is more frequent in individuals with ASD, often requiring coordinated care with neurologists and careful management of triggers, medications, and potential interactions with co-occurring conditions.

Epigenetics – literally, "above genetics"; the study of how environmental factors can produce heritable changes in gene expression without changing the underlying DNA sequence. More broadly, the set of developmental processes (and environmental influences) between genotype and phenotype. <https://pubmed.ncbi.nlm.nih.gov/27291929/>

Etiology – the cause or causes of a disease, condition or disorder.

ETP (Employment Training Program) - short-term internship program to prepare individual for a job, service taper off when job becomes permanent, and employer takes over paying wages.

Executive Dysfunction - difficulties with planning, organizing, and managing tasks.

GI (Gastrointestinal) Issues - in individuals with autism, commonly occurring problems such as constipation, diarrhea, and food sensitivities can affect behavior and overall health.

Group Home - a residential setting where individuals with developmental disabilities live in a small group and receive staff support for daily living and care needs.

Guardianship – the process in which one person is given the legal authority to make personal, health and financial decisions for an individual deemed unable to manage their own affairs. In NYS, full “17A” guardianship is highly restrictive, completely removing the individual’s rights to self-determination. Article 81 guardianship is a somewhat less restrictive form, granting some specific rights to the individual. An alternative approach is “[Supported Decision-Making](#)”, sometimes combined with appointment of a “Representative Payee” and a HIPAA release / healthcare proxy.

HCBS (Home and Community-Based Services) – in NYS, these include [OPWDD’s Com Hab](#) and [Day Hab](#) programs.

Health Care Transition - the process of moving from pediatric to adult medical care, requiring early planning to ensure continuity and providers who understand the needs of neurodiverse individuals.

High-functioning – an individual with average or above-average intelligence who is capable of managing [ADL’s](#) and life skills with minimal support (vs. “low-functioning” - these terms are no longer used, typically replaced with “low needs” and “high needs”)

Horizon - in NYC, one of two (along with [ASD Nest](#)) autism-focused classroom settings within the community school system. For intermediate level children with ASD who are able to participate and learn at grade level “with appropriate autism supports.” Horizon classes are self-contained, with up to 8 students, one special education teacher and one para, and include a curriculum to promote social communication. <https://www.schools.nyc.gov/learning/special-education/school-settings/specialized-programs>

ICF/IID’s (Intermediate Care Facility for Individuals with Intellectual Disabilities) - funded through Medicaid or Medicare, provide a more intensive level of Nursing and other care, for individuals with ID and more complex medical needs

ICT (Integrated Co-Teaching) class – a teaching model in which students with and without IEP’s learn together in the same classroom, in NYC with one general education and one special education teacher. <https://www.schools.nyc.gov/learning/special-education/school-settings/district-schools>

IDD (Intellectual and Developmental Disabilities) – a broad category of disabilities including neurodevelopmental and autism spectrum disorders co-occurring with intellectual disability.

Instrumental ADL’s – higher level Activities of Daily Living, such as shopping, preparing meals, housekeeping, doing laundry, traveling independently on public transportation (see also “[travel training](#)”), and managing finances.

Integrated Care - a holistic healthcare approach that focuses on coordinating medical, emotional, behavioral, and social care to address the needs of the individual as a whole.

Interdisciplinary Care - a collaborative approach where professionals from multiple disciplines work together to address the complex needs of an individual with ASD or other neurodevelopmental or medical disorder.

Internalizing disorders, behaviors (vs. externalizing) - psychological disorders or behaviors where distress is directed inward, such as anxiety or depression, as opposed to externalizing behaviors like aggression.

IRA Individual Residential Alternative – in supervised IRA’s, individuals receive room and board, live in a small group home and receive 24/7 staff support including Nursing, dietary, as well as financial decision-making support as needed.

ISH (Integrated Supportive Housing) – in NYS, an [OPWDD](#) apartment housing arrangement to support the individual living in their own apartment or with a roommate, and staff who check in intermittently (several times/week) to support medication administration, medical appointments and other needs.

ISS (Individual Supports & Services) – in NYS, a housing subsidy available through [OPWDD](#) for individuals with developmental disabilities who are living independently
<https://furmancenter.org/coredata/directory/entry/individual-supports-and-services-iss-housing-subsidy>

Lifeplan – In NYS’s [OPWDD](#) system, the document outlining the individual’s goals, habilitation goals, strengths and preferences, clinical and support needs, services and providers, and back-up plans. The Lifeplan is developed and refined in regular Lifeplan Meetings with the Care Coordinator, the individual, family members, and involved providers, which occur annually or semi-annually.

Lipid Panel - a blood test that measures cholesterol levels, including LDL, HDL, and triglycerides, to assess heart health and monitor side effects of certain medications, such as [antipsychotics](#).

Local diploma – in NYS, an alternative to the usual academic “Regents diploma” (based on passing 4 Regents exams), in which the student passes Regents exams with supports through the Safety Net program. A local diploma is an official high school diploma. Non-academic alternatives are the [CDOS](#) and the [SACCC](#). Note that Regents exams will be phased out in 2027.

Masking (also ‘camouflaging’) - when individuals with autism or other neurodiverse conditions suppress traits, such as [stimming](#) or unusual speech patterns, to conform to societal expectations.

Medication Titration - the process of adjusting medication doses, typically beginning with very low initial dosages when beginning a new medication, to achieve the desired effect while minimizing side effects, especially important in managing co-occurring conditions.

Metabolic Syndrome - a group of conditions, including high blood pressure, high blood sugar, abnormal cholesterol levels, and excess abdominal fat, that increase the risk of heart disease, stroke, and diabetes. Certain medications such as [antipsychotics](#) can cause over-eating and marked obesity, leading to risk of Metabolic Syndrome.

Neurodiversity – a term from neuroscience referring to the natural variation in human brain function and the wide range of differences in how people think, learn, process information and interact with the world. ‘Neurodiverse conditions’ include autism, ADHD, learning disabilities and dyslexia and tic disorders. Neurodiversity is also a perspective and a movement to recognize the strengths as well as challenges experienced by neurodivergent individuals, to push back against the conception of neurodiverse conditions as ‘disorders’, and to promote acceptance and inclusivity.

Neuropsychological evaluation - A comprehensive assessment that includes specific tests and tasks to measure psychological functions linked to particular brain structures and pathways, including measures of IQ, attention, learning and memory, reasoning, problem-solving, language, personality, and social-emotional functioning to guide diagnosis and intervention planning. Performed by a neuropsychologist (a PsyD or PhD psychologist). Typically performed over multiple sessions, and can cost between \$1500-\$6000.

“No wrong door” - a service model ensuring individuals and families can access the support they need through any service provider or agency, without being redirected or turned away.

NPS (Non-public school) – private or specialized schools that provide tailored educational services for students with disabilities. In NYS, schools serving students with disabilities whose educational needs cannot be met in public schools.

Obsessive-Compulsive Disorder (OCD) - a mental health condition characterized by intrusive thoughts (obsessions) and repetitive behaviors (compulsions) performed to relieve anxiety.

OPWDD (Office for People with Developmental Disabilities) – the New York State program which coordinates, manages and finances services for individuals with developmental disabilities, through Care Coordination Organizations (see [CCO's](#)) and approximately 500 nonprofit service providing agencies. <https://opwdd.ny.gov/>

Paid Neighbor –a service in which someone living nearby is paid to be on call and assist as needed. In NYS, this can be provided through [OPWDD](#)

Person-centered Care – healthcare that focuses on an individual’s needs, preferences and values, is respectful, compassionate, coordinated, and empowers individuals and families in making informed decisions about their health care.

Phenotypic expression –the observable traits or characteristics, such as behaviors or physical features, that result from the interaction of an individual’s genetic makeup and environment (see also “behavioral phenotype”)

PMDD (premenstrual dysphoric disorder) – mood disorder characterized by symptoms such as marked emotional lability, irritability, depression, or anxiety, alongside physical symptoms like fatigue, sleep changes, or physical pain. These symptoms occur during the luteal phase of the menstrual cycle and resolve shortly after menstruation begins, and can significantly impair social, occupational, or other areas of functioning.

Prodromal Symptoms - early warning signs of a medical or mental health condition, such as psychosis, which are crucial for early intervention and treatment.

Psycho-educational evaluation – an evaluation of a student’s cognitive, academic and social-emotional functioning to determine need for special educational services, typically including IQ, achievement and adaptive functioning testing. All students are entitled to a psychoeducational evaluation if parents (or school staff) are concerned about learning difficulties – and they are performed by Committee on Special Education (CSE) psychologists or special education professionals at no cost to families. Note that these evaluations will lead to an educational classification, but not a clinical diagnosis e.g. of ASD.

Psychological evaluation – a general term, also in NYS a specific requirement for [OPWDD](#) eligibility to have a psychological evaluation done within previous 3 years, which includes formal cognitive / IQ testing, adaptive testing, and proof of a neurodevelopmental diagnosis before 22 years of age. Done by a licensed psychologist with expertise in developmental disabilities.

Psychosocial evaluation – in NYS, a specific requirement for [OPWDD](#) eligibility, including a comprehensive social history, developmental and educational background, medical history, family and living situation and behavioral observation. Done by a licensed psychologist, sometimes in collaboration with social workers or developmental specialists.

Representative payee – a representative appointed to manage an individual’s finances and Social Security benefits – may be combined with a Supported Decision Making agreement.

Respite - temporary care provided to give family caregivers a break while ensuring the individual with disabilities receives proper support.

Restrictive Behavior - repetitive actions or limited interests that can interfere with daily life, common in individuals with ASD. Examples include strict adherence to routines or persistent focus on specific topics.

SACCC (Skills and Achievement Commencement Credential Certificate) – an alternative to an academic high school diploma for students with significant disabilities who take the NYS Alternate Assessment.

Selective Mutism - an anxiety disorder in which an individual is unable to speak in certain social situations despite being able to speak in others.

Self-Advocacy - the ability of an individual to understand and communicate their needs, rights, and desires, which is especially important for navigating transitions in healthcare and education.

Self-Advocate – in the [neurodiversity](#) field, an individual with a neurodivergent or a disability condition and the ‘voice’ to communicate their own experience, and exercise self-advocacy.

Self-Direction – in NYS [OPWDD](#), an option in which an individual / family selects, arranges and supervise their own services within an approved OPWDD budget. Requires a “Self-Direction Support Broker” and a “Fiscal Intermediary” to manage this program. <https://opwdd.ny.gov/types-services/self-direction>

Self-Efficacy – the belief in one’s ability to succeed at tasks and achieve goals, related to “agency” – the sense of controlling one’s own destiny. Both are major factors in self-advocacy and securing appropriate health and social services. <chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://educational-innovation.sydney.edu.au/news/pdfs/Bandura%201977.pdf>

SEMP – Supportive Employment Services – an [OPWDD](#) program that provides ongoing employment support for eligible individuals with neurodisabilities <https://opwdd.ny.gov/adm-2023-09-supported-employment-semp-0>. See also [ACCES-VR](#).

Sensory Processing - the way the brain receives, organizes, and responds to sensory input, such as sound, touch, and light. Challenges in sensory processing can lead to over- or under-reactions to stimuli. Sensory processing issues are typically addressed by Occupational Therapists.

‘Serve and return’ - Infant Mental Health term for the back-and-forth signaling and communication ‘volleys’ between an infant and caregiver that promote neuronal circuitry, child development and the strength of the [dyadic](#) unit

Site-based Prevocational Services – [OPWDD](#)-supported activities at an approved site meant to help develop skills and experience to lead to paid employment – tends to be repetitive type work (‘piecework’). See also ‘Community-based Prevocational Services’

SMI (Severe Mental Illness) – mental, behavioral or emotional disorder significantly limiting an individual’s ability to function in life activities – can include schizophrenia and bipolar disorder, with high likelihood of anosognosia (lack of awareness of one’s own condition), involvement with the criminal justice system, and preventable tragedy such as victimization or suicide.

Somatic - refers to physical symptoms that may have a connection to emotional or mental health conditions, such as headaches or stomachaches caused by stress.

Special Instruction – a tailored approach to teaching children with disabilities or developmental delays. In Early Intervention programs it is a term for special education/cognitive services

SSNR’s – Safe, stable, and nurturing relationships – the Infant Mental Health field stresses the importance of early parent-child [dyadic](#) relationships – i.e. when caregivers interact in caring and responsive ways to the infant, it builds the dyadic relationship and trust – supporting the infant’s sense of security to explore the world. <https://extension.psu.edu/programs/betterkidcare/news/support-early-relational-health-with-safe-stable-and-nurturing-relationships>

Stimming - short for self-stimulatory behavior, stimming refers to repetitive movements, sounds, or activities, such as hand flapping, rocking, or humming, often used by individuals with ASD to self-regulate emotions, sensory input, or stress. Stimming can help reduce anxiety or provide comfort but may become disruptive if it interferes with daily activities.

Supported Decision-Making – an alternative to [guardianship](#), in which a voluntary agreement sets forth collaborative arrangements for trusted supporters to help the individual make specified decisions, while the individual retains their legal rights.

TABS ID# - in NYS, a unique identifier assigned by [OPWDD](#) to track and manage services and supports provided to individuals with developmental disabilities.

Transition Planning – a coordinated process involving the individual, family, and providers to prepare for post-secondary education, employment, or independent living.

Trauma-Informed Care - an approach to care that acknowledges the impact of trauma on an individual's life and prioritizes emotional safety, trust, and empowerment.

Travel Training – teaching people with disabilities to use public transportation safely and independently, may include dealing with subway route changes, problem solving and safely walking as a pedestrian. In NY available as a service through [OPWDD](#), also in NYC through District 75's travel training program.

Trichotillomania - a mental health condition characterized by the compulsive urge to pull out one's hair, which can lead to noticeable hair loss and emotional distress.

Whole Person Care - a care model that emphasizes addressing all aspects of an individual's health and well-being, including physical, mental, emotional, and social needs.

<https://imconsortium.org/news/675300/ANNOUNCING-THE-NCCIH-COALITION-FOR-WHOLE-PERSON-HEALTH--AN-INVITATION-TO-JOIN-THE-MOVEMENT.htm>