

WHAT THEY NEVER TOLD US

Black Autism Acceptance & Awareness Day

SEPTEMBER 19

*“You can’t access
what nobody told
you **existed**.”*

Closing the information gap for
Black & under-served AUSOME families

Families deserve to know about:

-  Early Intervention
-  IEP & School Supports
-  Speech, OT & AAC
-  Medicaid & SSI
-  Respite & Waiver Services
-  Transportation Assistance



**FREE AUSOME FAMILY
RESOURCE GUIDE** >

*Stronger Families
Brighter Futures ♥*

DIFFERENT
BRILLIANT
VALUED
NEEDED
INCLUDED
ALWAYS ♥



THE AUSOME RESOURCE GUIDE WILL BE AVAILABLE FOR FREE DOWNLOAD AT

 **ISeeYouSeeInc.org** ON SEPTEMBER 19TH. 

A Buffalo & Western New York Family Resource Guide

Created by I See, You See Inc. • ISeeYouSeeInc.org

Resource information verified September 2026. Programs, eligibility rules, openings, and contact details may change.

Start Here:

Families should not have to know the right person, use the right words, or have extra money just to learn what support may be available to their child..

The purpose of this guide

To give Black and underserved Autism families a plain-language starting point: what to ask for, where to begin, what documents to keep, and who to call in Buffalo and Western New York.

A few things families are often not told:

- ☐ You can refer your own child to Early Intervention in Erie County if they are under age 3 and you have developmental concerns.
- ☐ You can request a special-education evaluation from your child's school district. You do not have to wait for the school to suggest it.
- ☐ A child may qualify for supports because of functional needs even when the family has been told to "wait and see."
- ☐ OPWDD, SSI, Medicaid transportation, respite, AAC, parent advocacy, and family support are separate systems. Applying to one does not automatically connect you to all the others.
- ☐ A denial is not always the end. Ask for the reason in writing, the appeal or review process, and what documentation is missing.

How to use this guide

1. Circle or highlight the sections that match your child's current needs.
2. Use the "What to say" scripts when calling agencies or schools.
3. Keep a folder with evaluations, IEPs, medical records, denial letters, contact names, and application dates.
4. Use the Resource Roadmap near the end of this guide to track your next steps.

Important

This guide is educational and is not legal or medical advice. Eligibility is determined by each program. If a situation is urgent or unsafe, contact the appropriate emergency service or your child's medical team.

Early Intervention: Birth to Age 3

New York's Early Intervention Program supports infants and toddlers with developmental delays or qualifying conditions. In Erie County, the program is voluntary, and there is no cost to families.

Services may include

Speech & communication Speech-language services and support for communication development.	Occupational therapy Fine-motor, sensory, self-help, and daily living support.
Physical therapy Gross-motor, movement, balance, and mobility support.	Family support Family education, counseling, parent support, social work, and home visits.
Assistive technology Devices and services that support communication or participation.	Service coordination A coordinator helps families understand the process and connect services.

What they may not tell you

Parents and guardians can make the referral themselves. You do not have to wait for a pediatrician, daycare, or other professional to do it.

What to say when you call

"I am the parent/guardian of a child under age 3, and I have concerns about their development. I would like to make an Early Intervention referral and learn about the evaluation process."

Erie County Early Intervention

Phone: 716-858-6161 | 95 Franklin Street, Room 837, Buffalo, NY 14202

Website: <https://www3.erie.gov/health/early-intervention-program>

Ask about:

- ☐ The developmental evaluation
- ☐ An IFSP if your child is eligible
- ☐ Service coordination
- ☐ Developmental monitoring (if your child is not eligible, Transition planning as your child approaches age 3)

YOU CAN PUT THE REQUEST IN WRITING

School Supports: Evaluations, IEPs & Accommodations

In New York, special education is provided through the Committee on Preschool Special Education (CPSE) for preschool-aged children and the Committee on Special Education (CSE) for school-age students.

Your child does not have to “fail first.”

If you suspect a disability is affecting learning, communication, behavior, participation, or access to school, you can ask the district for an evaluation. Keep a dated copy of your written request.

An IEP may address

- ☐ Specialized instruction and measurable annual goals
- ☐ Speech-language therapy, occupational therapy, physical therapy, counseling, or other related services when appropriate
- ☐ AAC or assistive technology evaluations and supports
- ☐ Sensory, communication, behavioral, testing, seating, scheduling, or environmental accommodations
- ☐ Transportation, extended school year, paraprofessional support, or other services when required by the student's needs
- ☐ Transition planning as the student gets older

What to say:

“I am requesting a comprehensive special-education evaluation because I have concerns about my child's communication, learning, sensory needs, behavior, and/or ability to access the school day. Please treat this as my written referral and provide me with the next steps and my procedural safeguards.”

Before an IEP meeting, ask yourself:

- ☐ What is hardest for my child during a normal school day?
- ☐ What support helps at home or in the community?
- ☐ What skills do I want my child to gain this year?
- ☐ What data is the school using to say a service is or is not needed?
- ☐ Does the IEP describe what my child actually needs - or only what the school currently has available?

Free local help

Parent Network of WNY provides 1-on-1 support, workshops, and information to help families understand disabilities, special education, and service systems.

English: 716-332-4170 • Español: 716- 449-6394 • Toll Free: 866-277-4762.

New York parent guide: NYSED Special Education Parent's Guide

<https://www.nysed.gov/special-education/parents-guide-special-education>

Communication, Therapy, Sensory & Daily Living Supports

A child who is struggling maybe communicating a need: difficulty understanding language, sensory overload, pain, anxiety, fatigue, motor challenges, or an environment that does not fit.

Support that families may want to ask about

Speech-language therapy Receptive language, expressive language, social communication, speech sounds, and functional communication.	AAC evaluation Communication boards, picture systems, speech-generating devices, or other tools for children who need additional ways to communicate.
Occupational therapy Sensory processing, fine motor, handwriting, dressing, feeding participation, routines, and self-care.	Feeding support For significant food selectivity, oral-motor concerns, nutritional risk, or mealtime difficulties. Ask whether medical causes need to be ruled out.
Behavioral support Goals should be individualized, respectful, functional, and focused on safety, communication, independence, and quality of life.	Mental health support Autistic children can also experience anxiety, ADHD, depression, trauma, sleep problems, or other concerns that deserve appropriate evaluation and support.

AAC does not “give up on speech.”

AAC gives a child another way to communicate. Ask for an evaluation when speech alone is not meeting the child's communication needs.

Questions to ask any provider

- ☐ What are the goals, and how were they chosen?
- ☐ How will my child's communication, comfort, consent, and sensory needs be respected?
- ☐ How will progress be measured and shared with me?
- ☐ What can we practice in everyday routines without turning home into therapy all day?
- ☐ What are the alternatives if this approach is not a good fit?
- ☐ Will insurance or Medicaid cover this, and is prior authorization required?

OPWDD, Care Management & Respite

The New York State Office for People With Developmental Disabilities (OPWDD) is a major pathway to long-term developmental disability supports. Autism can be a qualifying developmental disability, but eligibility must be established through the OPWDD process.

Start with the OPWDD Front Door

Call 866-946-9733 and tell them the county where you live. Ask how to begin eligibility and what documentation is required.

Depending on eligibility, need, availability, and waiver enrollment, supports may include

- ☐ Care management / care coordination
- ☐ Respite so caregivers can take a break while the individual is safely supported
- ☐ Community habilitation and skill building
- ☐ Family support services
- ☐ Self-direction and individualized budgets
- ☐ Day, employment, community, and residential supports as the person gets older

Documents to start gathering

- ☐ Autism/developmental evaluations
- ☐ Psychological or neuropsychological testing
- ☐ Adaptive functioning information
- ☐ Medical records related to the developmental disability
- ☐ School records and IEPs
- ☐ Proof of identity/residency and insurance information as requested

If the paperwork feels overwhelming

Ask a Care Coordination Organization, Parent Network of WNY, or a disability service agency to explain the steps. Keep copies of every document you submit and write down dates and names.

Local respite example

People Inc. offers OPWDD-funded respite and other developmental disability services across Western New York. General/Admissions: 716-817-7400. Eligibility and openings vary.

<https://www.people-inc.org/respite/>

A REFERRAL IS USELESS IF YOU CANNOT GET THERE

Medicaid, Transportation & Getting to Care

Transportation, insurance rules, time off work, and provider availability are real access barriers. Ask about these supports early - not after appointments are missed.

NYS Medicaid non-emergency medical transportation

New York Medicaid can cover authorized transportation to and from Medicaid-covered medical services. In Erie County and other upstate counties, trips are arranged through Medical Answering Services (MAS).

Upstate MAS: 866-932-7740

Plan ahead: NYS advises contacting MAS at least 72 hours before a non-urgent appointment when possible.

NYS Medicaid Transportation -

https://www.health.ny.gov/health_care/medicaid/members/medtrans_overview.htm

Ask about

- ☐ Public transit, taxi, ambulance, or other medically appropriate transportation
- ☐ Mileage reimbursement when an eligible family uses a personal vehicle
- ☐ What medical-necessity forms are needed for a particular transportation level or an out-of-area provider
- ☐ Whether the therapy/provider accepts your child's insurance before scheduling repeated visits
- ☐ Telehealth when clinically appropriate and available

For needs beyond medical appointments

211WNY connects families to food, housing, utilities, child care, transportation, mental health, disability, and other community resources. Dial 2-1-1 or visit [211WNY.org](https://211wny.org).

SSI & Financial Supports

Supplemental Security Income (SSI) can provide monthly payments to some children with qualifying disabilities when household income and resources meet Social Security rules.

SSI looks at two broad areas

Financial eligibility

Social Security considers household income and resources under specific rules.

Disability eligibility

The child must have a medically determinable impairment that results in marked and severe functional limitations and meets duration requirements.

Autism diagnosis alone does not automatically approve SSI.

The decision considers the child's functional limitations and the program's financial rules. School, medical, therapy, and caregiver information can all help document how the child functions day to day.

Helpful records to organize

- ☐ Diagnostic reports
- ☐ IEPs, school evaluations, attendance and behavior/support records Speech, OT, PT, behavioral, feeding, and mental-health records Medication and medical records when relevant
- ☐ A simple caregiver description of what your child needs help with compared with same-age peers

Social Security: SSI for Children :<https://www.ssa.gov/faqs/en/questions/KA-10055.html>

Also ask local agencies about:

- ☐ Family reimbursement or Family Support Services when available
- ☐ Recreation scholarships or inclusive program funding Utility, food, housing, and child-care assistance
- ☐ ABLE accounts or benefits planning as your child gets older

For Black & Underserved Families: Make the System Explain Itself

Bias, rushed appointments, transportation, work schedules, insurance, provider shortages, and confusing systems can all affect access. The answer is not for families to become perfect navigators - systems must become easier to reach and understand.

A powerful question

“What service, referral, evaluation, accommodation, benefit, or program would you tell a family with more time, money, or system knowledge to ask about right now?”

When you feel dismissed, try these questions

- ☐ Can you document my concern and your recommendation in the record?
- ☐ What criteria are you using to make that decision?
- ☐ What would make my child eligible?
- ☐ Is there another program, provider, funding source, or level of care I should ask about?
- ☐ If you are denying this request, can I have the denial and appeal/review process in writing?
- ☐ Who is the supervisor, family navigator, care manager, or parent advocate I can speak with?

Build your paper trail

Write down names

Record the date, agency, person you spoke with, and what they told you.

Save copies

Keep referrals, evaluations, applications, IEPs, approvals, denials, emails, and letters.

Follow up in writing

After an important call, send an email summarizing your understanding and asking for corrections.

Track deadlines

Write down appeal deadlines, recertification dates, IEP dates, and follow-up appointments.

You are allowed to bring support.

For school or service meetings, ask whether you may bring a trusted family member, advocate, care manager, or support person. You do not have to process complicated information alone.

Buffalo & WNY Resource Directory

This is a starting list, not an endorsement or a complete directory. Call ahead to confirm eligibility, insurance, waitlists, service area, and openings.

RESOURCE	WHY CALL	PHONE NUMBER
Erie County Early Intervention	Birth-under 3 developmental evaluation and services; parent self-referral	716-858-6161
Parent Network of WNY	Free 1-on-1 family support, special education, disability services, workshops	716-332-4170; Español 716-449-6394
NYS OPWDD Front Door	Start OPWDD eligibility and access to developmental disability supports	866-946-9733
People Inc.	OPWDD HCBS services, respite, family/community supports across WNY	716-817-7400
The Summit Center	Autism/developmental education, early autism, behavioral health, training, community/adult programs	716-629-3400
NYS Medicaid Transportation / MAS	Authorized transportation to Medicaid- covered medical appointments	866-932-7740
211 WNY	24/7 connection to health and human services including food, housing, disability and family resources	Dial 2-1-1
Social Security - SSI	SSI information and application guidance for children with disabilities	SSAnational services
NYSED Special Education Parent Guide	New York parent rights, referrals, evaluations, IEP process and procedural protections	Online resource Website on page 3

Need a broader list?

Parent Network of WNY maintains updated local directories, including developmental disability Family Support Services and recreation resources. 211 WNY is also useful when autism-specific needs overlap with food, housing, utilities, child care, transportation, or other family needs.

My Child's Resource Roadmap

Pick the next 3 steps. You do not have to solve every system this week.

NEED	MY NEXT STEP	DONE
Development	I have concerns and need an evaluation / Early Intervention referral.	☐
School	I need to request or review an evaluation, IEP, 504 plan, AAC, therapy, or accommodation.	☐
Communication	I want to ask about speech-language services or an AAC evaluation.	☐
Sensory / daily living	I want to ask about OT, feeding, self-care, or sensory supports.	☐
OPWDD	I need to start or finish eligibility / Front Door steps.	☐
Respite	Our family needs caregiver relief or structured support.	☐
Transportation	Getting to appointments is a barrier.	☐
SSI / finances	I want to screen for SSI or other financial supports.	☐
Family navigation	I need a person to help me understand what to do next.	☐
Basic needs	Food, housing, utilities, child care, or transportation are affecting our ability to follow through.	☐

My three next steps

1. _____
2. _____
3. _____

Questions I need answered

Contact & Application Tracker

Use this page to record calls, applications, referrals, meetings, and promised follow-ups.

DATE	AGENCY / PERSON	WHAT I ASKED	NEXTSTEP / DEADLINE	DONE
				☐
				☐
				☐
				☐
				☐
				☐
				☐

Documents I have gathered

- ☐ Diagnostic/developmentalevaluation
- ☐ IEP/504/school evaluations
- ☐ Therapy reports
- ☐ Medical records
- ☐ Insurance/Medicaid information
- ☐ OPWDD paperwork
- ☐ SSI paperwork
- ☐ Denial/approval letters
- ☐ My notes and contact log

Remember

Getting support can be a process. Every call you make, question you ask, referral you submit, and document you save makes the next step easier. You deserve clear information and a system that helps your family move forward.

I See, You See Inc. • Educate • Advocate • Connect • Empower

ISeeYouSeeInc.org

Verified Sources & Reference Links

These official and local sources were used to verify the guide. Always check the current website or call the program before relying on eligibility details, deadlines, or service availability.

Erie County Department of Health - Early Intervention Program -

<https://www3.erie.gov/health/early-intervention-program>

New York State Education Department - Parent's Guide to Special Education -

<https://www.nysed.gov/special-education/parents-guide-special-education>

New York State Education Department - Individualized Education Program (IEP) -

<https://www.nysed.gov/special-education/individualized-education-program-iep>

NYS Office for People With Developmental Disabilities - Front Door / Family Resources -

<https://opwdd.ny.gov/access-supports>

NYS Department of Health - Medicaid Transportation -

https://www.health.ny.gov/health_care/medicaid/members/medtrans_overview.htm

Social Security Administration - SSI for Children - <https://www.ssa.gov/faqs/en/questions/KA-10055.html>

Parent Network of WNY - <https://parentnetworkwny.org/>

211 WNY - <https://www.211wny.org/>

People Inc. - Respite and Developmental Disability Services - <https://www.people-inc.org/respite/>

The Summit Center - <https://thesummitcenter.org/>

Share this guide

Families are welcome to use this guide as a starting point for questions and referrals. Organizations should verify program details before reproducing time-sensitive contact or eligibility information.