Certified Residence Guide for People with Developmental Disabilities and Their Families

Connecting and supporting families of individuals with special needs
Parent to Parent of NYS

Parent to Parent of NYS is a statewide not for profit organization with a mission to support and connect families of individuals with special needs. We are a point of contact for many parents who are ‘getting started’ on their journey of parenting a child with developmental disabilities. There are 15 offices throughout NYS, staffed by Regional Coordinators, who are parents or close relatives of individuals with special needs. A website is maintained to provide information and events listings - www.parenttoparentnys.org

In addition to the Parent Matching program, the organization fields telephone calls from parents of children with special needs who are looking for resources, services and information. Calls include parents looking for information about medical services and therapies and those looking for information specifically about an illness or disability. There are often questions about special education. All programs are based on the philosophy of parents helping each other, drawing on a network of parents helping parents. Coordinators are there to assist, but draw on other parents to help. There is no charge for services.

Family Partners for Change

Family Partners for Change is a partnership of families and service provider representatives from Western New York. This group has been working together to find ways to improve communication and trust between the families and service providers.

There was much discussion about what would make the transition easier for families, staff and the person who is moving into a residence for the first time. Dispute resolution, policies and procedures and family involvement are also key points.

After much discussion and editing the partners put together a packet of information and guidelines to help families and providers with the transition process from family home to certified housing. Our hope is that families and service providers will see this information and guidelines as useful tools.

Mission Statement of Family Partners for Change:
Service recipients, families, guardians and service providers will partner to foster open and honest communication, trust, sensitivity and mutual respect with the goal of achieving the quality of services and quality of life the person truly deserves.

For more information regarding housing or Family Partners for Change contact:

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Certified Residential Options

Following are detailed descriptions of the various certified residential options that may be available to people with disabilities in your area:

Family Care Homes

Housing and supports are provided in a family setting other than the biological family. The host family receives funds to provide clothing, food, shelter, and living expenses. In some instances, funds for personal care services are also provided.

Certified Homes

*The state or a non-profit agency owns or leases a home certified by OPWDD. There are state mandated regulations on how the home is run and staffed and how many people can live there.*

ICF - Intermediate Care Facility — 24-hour staff - Higher level of care. May have many medical or other health care needs, may require full time nurse, or have nutritional needs.

CR - Community Residence — 24-hour staff — more structured - tend to be large homes.

IRA - Individual Residential Alternative — 24-hour staff — structure varies — could be home or apartment

Supervised Apartments - 24-hour staff assisted

Supportive Apartments - Some staff assistance but not 24 hours

**NYS Cares wait list (WNYDDSO – NYCare's Residential Registry)** - This is what your local DDSO and OPWDD uses to find out about people, their needs and the time frame. One of the needs could be certified residential opportunities and how far into the future you are anticipating the move. You should talk to your Medicaid Service Coordinator to make sure that your family member is on the list/registry.

If you are interested in actively pursuing a placement in a certified residence for your family member in the next few years, you need to discuss this with your Medicaid Service Coordinator. Your MSC will help you find what is available in your area. You are not moving up the list of certified residential opportunities if you are on the NYS Cares Wait list / NYCares Residential Registry - Your MSC helps you find the residential opportunities that are available.
Role of Medicaid Service Coordinator (MSC) in Residential Placement

- MSC role is to advocate, link, refer to any needed services using person centered planning process. The MSC meets with individual and family monthly as well as 2 times per year for Individualized Service Plan (ISP). Please note, you have the right to request a new MSC and/or service provider at any time.

- MSC will meet with the team to determine when the Residential Service is anticipated i.e., 2 years, 5 years, or 10 years. The MSC completes the New York State Creating Alternatives in Residential Environments and Services (NYSCARES) application for Residential Placement.

- Priority Levels
  - 1st - Urgent need/Emergency – abusive/neglectful situation
  - 2nd - Emergency prevention – aging/failing health of caregiver
  - 3rd – Non urgent – request future placement (within 5 years).

- MSC will complete a variety of tasks including, but not limited to, Respite In home, Out of Home Respite, In-home Residential Habilitation, and Recreational Respite applications.

- When Residential Habilitation is an option you may need to decide which environment is best. Some things you might want to consider are:
  - staffing ratio
  - medical concerns
  - level of supervision
  - adaptive environments
  - behavioral supports
  - tour options

- MSC will assist the family in determining which living environment would support the individual needs.

- MSC will complete needed paperwork to agencies providing Residential Habilitation options.

- Your Residential Habilitation provider and Medicaid Service Coordination provider does not need to be from the same agency.
Provider to Family Information Fact Sheet
Guidelines for providers and families

Rights and Responsibilities

Describe the rights and responsibilities of family members

Describe the rights and responsibilities of the individual planning to receive service and support

Describe the providers approach to an individual’s rights in sexual expressions

Describe how the provider deals with the inventory, purchasing, repairing and replacement of individual personal property

Describe how the provider handles objection to treatment

Describe to family how the provider interacts with parents, other family members, guardians, and advocates. Include information on visits to the home and visits to families’ homes.

Describe how the Agency works to develop and sustain Parent Support Groups

Safety

Describe how the provider accesses, plans, and reviews how to ensure an individuals safety. Include the document that outlines an individual’s strengths and areas that require support from the provider

Describe how provider will work with family to ensure safety measures and supports the individual requires are implemented.

Describe the fire safety practices for the home or living arrangement

Staff

Provide as copy of or review with family the staff supports available. This can be done through staffing pattern and discussion of minimum safe staffing level.

Outline the type, frequency of staff training.

Medical

Describe how medical appointments are managed.

Describe the provider’s position on health care proxies and other advance directives

Describe how the provider provides supports in the following areas:

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Medication Administration

Staff support in medication administration

Over the counter medication

On call nursing/ doctor supports

Informed consent for medical, behavioral and planning purposes

Financial
Provide to family liability documents as required by OPWDD and explain the impact on payments for services and supports

Describe how the provider claims the funds they receive for the service provided. Include how the individual and family can support the maximization of the funding

Describe the role of personal allowance and the responsibility of the provider if they act as representative payee or if someone else or the person themselves act as representative payee

Describe the type of documentation of spending of personal allowance and how it is shared.

Describe what a personal expenditure plan is and the review process

Describe the statement of fees and services

Describe what types of support in the area of transportation the home will provide.

Describe the practices of the Agency in the following area – purchasing food and food preferences (i.e. snacks, eating out, healthy choices), personal hygiene supplies

Describe the role of food stamps

Records
Describe to the family and person the provider’s process for access to records and other confidential documents (i.e. ISP, Res Hab Plan, monthly notes, etc…)

Confidentiality
How does the Agency address the sharing of private information?

Long Term Planning

1. Discuss with a family considering or currently acting as legal guardian how that guardianship status
impacts end of life planning and burial planning.

2. Describe how a stand by guardian becomes the primary guardian.

3. Describe the options for burial planning with families so as to make preparations in advance. This will help families feel their child has plans if they are not present.
   - Burial Trusts
   - Burial Savings Account
   - Life Insurance Policy

4. Describe how the Agency handles funerals under the following circumstances:
   - Burial Planning and Trust Complete
   - Burial Planning with a Savings Account and or Life Insurance
   - Burial Planning with only available personal allowance and Agency support

Contact Sheet

Please provide to the person, their family and others involved the following contact information

House Manager_________ Phone #_________________ Email address________________________________
Manager’s supervisor_____ Phone #_______________ Email address_______________________________
House Nurse___________ Phone #_________________ Email address_______________________________
MSC___________________ Phone #_________________ Email address_______________________________
MSC’s supervisor_______ Phone #_______________ Email address_______________________________
Quality Assurance_______ Phone #_________________ Email address_____________________________
Director_______________ Phone #_________________ Email address_______________________________
Executive Director_______ Phone #_________________ Email address_____________________________

* Provide family the contact information for the Developmental Disabilities Service Office, Commission of Quality Care, Advocacy for Persons with Disabilities and other external monitoring Agencies as necessary.
RIGHTS OF PARENTS AND LEGAL GUARDIANS

What is a right? A right is an existing lawful privilege

1. Each one of you must be informed of the rights your relative is entitled to at this facility. Be informed of your relatives rights under law and regulation and such rights shall not be abridged or violated.

2. Each parent must be informed of their relatives’ medical condition. If your individual is suspected or diagnosed as having health problems requiring emergency room or hospitalization, you must be notified.

3. You have the right to consent for medical, dental treatment, health and hospital services, the right to obtain a second opinion and informed consent.

4. Upon an individual meeting the criteria, you have the right to consent to a DNR (No Not Resuscitate) order and the right to revoke that consent at any time.

5. You must be informed of your relatives’ developmental and behavioral status, attendant risks of treatment and the right to refuse treatment.

6. You have the right to review your relatives’ financial records upon request.

7. Right to receive a written invitation to participate in the semi annual review.

8. Right to receive a copy of the complete ISP (Individual Service Plan) upon request.

9. Be allowed to review all of your relative’s records, with a designated staff person.

10. Be notified in writing of a behavior management plan which seeks to employ the use of restrictive techniques and to consent to the use of such techniques.

11. You have the right to visit at any reasonable hour.

12. The right to be notified of any serious reportable incident or allegation of residents abuse within 24 hrs, unless there is written advice from you that you do not want to be notified.

13. You shall be informed that you may request information of the actions taken to protect your individual if abuse is alleged to have taken place.

14. As per Jonathan’s Law, you have the right to request information on the status and or resolution of an abuse allegation if abuse is alleged to have taken place. This request should be written. The investigation will be redacted.
15. You have the right to discuss your concerns or complaints without fear or reprisal with a variety of agencies and/or bodies including the DDSO Director; Mental Hygiene Legal Services; individuals Rights Committee chairman; Commission on Quality Care located in Albany (800-624-4143); Commissioner of OPWDD (518-473-1997); President of the Board of Visitors; and the ombudsman.

16. You have the right to be advised of your right to object to and appeal your relative’s service plan and other proposals to change a person’s residential placement, both on the grounds of the facility and moving into the community. Parents, guardians, or correspondents may object to and appeal any plan, or care, or treatment with which they disagree, including plans for placement or a proposal initiated by the agency/facility to discharge. You may select a representative of your choosing to provide assistance and/or representation including legal counsel. Objecting may take form in an informal manner or a formal process, which is called due process. In simpler language it means you have the right to a quick, fair, and impartial meeting to discuss your complaint or objection.

17. All information above shall be presented in a truthful manner.
Acronyms List

ac-ro-nym

(ak’-ro-nym’) - The dictionary defines acronym as a word formed from the initial letter of a name or by combining the initial letters or parts of a series of words. The New York State Office of Mental Retardation and Developmental Disabilities and its constituents commonly use acronyms as a sort of shorthand version for referring to many of the aspects of its business. For your convenience, the following is a listing of the most commonly used acronyms.

A
AAA Area Agency on Aging
AA/HRC Affirmative Action/Human Relations
AAIDD American Association of Intellectual and Developmental Disabilities
ABSS Applied Behavioral Sciences Specialist
AC Augmentative Communication
ACD Alternate Care Determination
ACS Administration of Children’s Services
ADA Americans with Disabilities Act
ADC Adult Day Care
ADL Activities of Daily Living
AES Adaptive Equipment Specialist
AFDC Aid to Families with Dependent Children
AIDS Acquired Immune Deficiency Syndrome
AILCNY Association of Independent Living Centers in New York Inc.
AMAP Approved Medication Administration Personnel
ASFC Agency Sponsored Family Care
AT Assistive Technology

B
BMC Behavior Management Committee
BOCES Board of Cooperative Education

C
CAB Consumer Advisory Board
CAH Care At Home
CAP Client Assistance Program (Willowbrook)
CAPA Child Abuse Prevention Act
CASA Community Alternative Systems Agency
CBVH Commission for the Blind & Visually Handicapped
CCF Council on Children & Families
CCSI Coordinated Children’s Services Initiatives
CDC Centers for Disease Control & Prevention
CDPC Program Consumer Directed Personal Care Program
CDPAP Consumer Directed Personal Assistance Program
CDL Commercial Drivers License
CEO Chief Executive Officer
CFR Consolidated Fiscal Report
CFS Children and Family Services (New York State)
CHAS Comprehensive Housing Affordable Strategy
CHHA Certified Home Health Agency
CHIP Children’s Health Insurance Program, the federal program that provides funds for state Children’s health care such as New York’s Child Health Plus
CHP Child Health Plus, New York’s insurance plan for low income children
CI Community Inclusion
CIN Client Identification Number, the number used for Medicaid identification purposes on benefit card.
CIT Center for Intensive Treatment
CM Case Management
CMCM Comprehensive Medicaid Case Management
CMS Center for Medicare and Medicaid Services
COIL Coalition on Independent Living
COMPASS Consumerism, Outcome, Management Plan, Agency Self Survey
CON Certificate of Need
COTA Certified Occupational Therapy Assistant
CP Cerebral Palsy
CPA Child Protective Agency
CPEP Comprehensive Psychiatric Emergency Program
CPSE Committee on Preschool Special Education
CQC Commission on Quality of Care
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADP</td>
<td>Advocacy for Persons with Disabilities</td>
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<tr>
<td>CR</td>
<td>Community Residence</td>
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<tr>
<td>CSE</td>
<td>Committee on Special Education</td>
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<tr>
<td>CSEA</td>
<td>Civil Service Employees Association</td>
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<tr>
<td>CSP</td>
<td>Community Services Plan (formerly CSEP)</td>
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<tr>
<td>CSS</td>
<td>Consolidated Support and Services</td>
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<tr>
<td>CSW</td>
<td>Certified Social Worker</td>
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<tr>
<td>DARS</td>
<td>Division of Administration &amp; Revenue Support</td>
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<tr>
<td>DC</td>
<td>Developmental Center</td>
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<tr>
<td>DD</td>
<td>Developmental Disabilities</td>
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<tr>
<td>DDAWNY</td>
<td>Developmental Disabilities Alliance of WNY</td>
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<tr>
<td>DDP</td>
<td>Developmental Disabilities Profile</td>
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<tr>
<td>DDP4</td>
<td>Developmental Disabilities Profile (Request for Services Form)</td>
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<tr>
<td>DDPC</td>
<td>Developmental Disabilities Planning Council</td>
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<tr>
<td>DDSO</td>
<td>Developmental Disabilities Services Office</td>
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<tr>
<td>DME</td>
<td>Durable Medical Equipment</td>
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<tr>
<td>DNR</td>
<td>Do Not Resuscitate</td>
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<tr>
<td>DOB</td>
<td>Date of Birth</td>
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<tr>
<td>DOB</td>
<td>Division of Budget</td>
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<tr>
<td>DOH</td>
<td>Department of Health</td>
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<tr>
<td>DQA</td>
<td>Division of Quality Assurance (OPWDD)</td>
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<tr>
<td>DSS</td>
<td>Department of Social Services</td>
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<tr>
<td>DTx</td>
<td>Day Treatment</td>
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<tr>
<td>DVE</td>
<td>Diagnostic Vocational Education</td>
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<tr>
<td>EBT</td>
<td>Electronic Benefit Transfer</td>
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<tr>
<td>ECDC</td>
<td>Early Childhood Direction Centers (State Education Department)</td>
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<tr>
<td>ECDMH</td>
<td>Erie County Department of Mental Health</td>
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<tr>
<td>ECMC</td>
<td>Erie County Medical Center</td>
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<tr>
<td>EHC</td>
<td>Elmwood Health Center</td>
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<tr>
<td>ED</td>
<td>Emotionally Disturbed</td>
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<tr>
<td>EIP</td>
<td>Early Prevention Program</td>
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</table>
ICF/DD  Intermediate Care Facility for the Developmentally Disabled
ICF/MR  Intermediate Care Facility for the Mentally Retarded
IDEA  Individuals with Disabilities Education Act (federal)
IEP  Individualized Education Plan
ILC  Independent Living Center
IPP  Individual Program Plan
IPOP  Individualized Plan of Protective Oversight
IPR  Independent Professional Review
IRA  Individualized Residential Alternative
IRWE  Impairment Related Work Expense
ISE  Individualized Service Environment
ISP  Individualized Service Plan
ISPM  Individualized Services Planning Model
ISS  Individual Support Services
IT  Interdisciplinary Team
ITT  Interdisciplinary Treatment Team
IUR  Independent Utilization Review

J  (There are no acronyms beginning with J at this time)

K
KOB  Kids on the Block

L
LCED  Level of Care Eligibility Determination
LD  Learning Disability
LDANSY  Learning Disabilities Association of New York State
LDSS  Local Social Services District
LGU  Local Government Unit
LHA  Local Housing Authorities
LHCSA  Licensed Home Care Services Agency
LOC  Level of Care
LRE  Least Restrictive Environment
LSC  Life Safety Code
LSED  Legal Services for Elderly, Disabled or Disadvantaged of WNY
LTHHCP  Long Term Home Health Care Program
MA  Medicaid  
MAR  Medication Administration Record  
MCO  Managed Care Organization  
MDU  Multiple Disability Unit  
MH  Mental Health  
MHL  Mental Hygiene Law  
MHLS  Mental Hygiene Legal Service  
MMIS  Medicaid Management Information Systems  
MOA  Memorandum of Agreement  
MOU  Memorandum of Understanding  
MSC  Medicaid Service Coordinator  
MSW  Masters in Social Work  

NASDDDS  National Association of State Directors of Developmental Disabilities Services, Inc.  
NF  Nursing Facility  
NFPA  National Fire Protection Association  
NI  Neurologically Impaired  
NIMBY  Not in my Backyard  
NLS  Neighborhood Legal Services  
NOD  Notice of Determination  
NP  Nurse Practitioner  
NPC  Neighborhood Preservation Corporation  
NYCRR  New York Codes, Rules & Regulations  
NYSARC (formerly, New York State Association for Retarded Citizens, Inc.)  
NYSACRA  New York State Association of Community and Residential Agencies  
NYCARES  New York State Creating Alternatives in residential Environment & Services  
NYSADSP  New York State Association of Day Services Providers  
NYSDOH  New York State Department of Health  
NYSRA  New York State Rehabilitation Association  
NYSSAC  New York State Society for Autistic Children  

Distributed by Parent to Parent of NYS   www.parenttoparentnys.org
O
OCS Office of State Comptroller
OMH Office of Mental Health
OPTS Opportunities for People Through Services
OPWDD Office For People With Developmental Disabilities
OSERS Office of Special Education & Rehabilitation Services (federal)
OSES Office for Special Education Services (State Education Department)
OSHA Occupational Safety & Health Administration
OTR Occupational Therapy or Therapist (Registered)
OTA Office of Temporary Assistance
OTR Registered Occupational Therapist

P
PA Physician’s Assistant
PA Provider Agreement
PA Public Assistance
PAC Products of Ambulatory Care
PASS Plan for Achieving Self Support
P/PM Policy & Procedures Manual
PCA Personal Care Aide
PCP Person Centered Planning
PDD Pervasive Developmental Disorder
PHI Protected Health Information
PISP Preliminary Individualized Service Plan
POCA Plan of Corrective Action
POPO Plan of Protective Oversight
PONS Plan of Nursing Service
PPA Prior Property Approval
PRC Priority Review Committee
PRWORA Personal Responsibility and Work Opportunity Act
PRI Patient Review Instrument
PS Personal Service
PT Physical Therapy or Therapist
PWS Prader-Willi Syndrome
Q
QA  Quality Assurance
QI  Quality Improvement
QMRP Qualified Mental Retardation Professional

R
Res Hab Residential Habilitation
RFA  Request for Application
RFS  Request for Services
RN  Registered Nurse
RPC  Rural Preservation Corporation
RRTC Rehabilitation Research & Training Center
RSFO Revenue Support Field Office

S
SC  Service Coordinator
SCA  Standard Compliance Analyst
SCOR Service Coordination Observation Report
SCP  Senior Companion Program
SCIP  Strategies for Crisis Intervention & Prevention
SCIP-R Strategies for Crisis Intervention & Prevention- Revised
SD  Self Determination
SED  State Education Department
SEQRA State Environmental Quality Review Act
SETRC Special Education Training & Resource Center
SLP  Speech/Language Pathology
SNT  Supplemental Needs Trust
SOCR State Operated Community Residence

SOD  Statement of Deficiency

SODH State Operated Day Habilitation

SOFA State Office for the Aging

SOICF State Operated Intermediate Care Facility

SOIRA State Operated Individual Residential Alternatives

SRC or SIRC Special Review Committee or Special Incident Review Committee

SP  Speech Pathology

SSA  Social Security Administration

SSDI Social Security Disability Insurance

SSI  Supplemental Security Income

TABS Tracking and Billing System

TADA Temporary and Disability Assistance

TANF Temporary Assistance Needy Families

TASH The Association for Persons with Severe Handicaps

TBI  Traumatic Brain Injury

TBISCC Traumatic Brain Injury Services Coordinating Council

TDD  Telephone Device for the Deaf

TPHI  Third Party Health Insurance

TRAID Technology-Related Assistance for Individuals with Disabilities

TRO  Temporary Restraining Order

TTY Teletypewriter

TUBS Temporary Use Beds
U

UCPA United Cerebral Palsy Association

UR Utilization Review

V

VA Veterans Administration
VESID Vocational & Educational Services for Individuals with Disabilities

VO Valued Outcome

VOCR Voluntary Operated Community Residence

VODH Voluntary Operated Day Habilitation

VOICF Voluntary Operated Intermediate Care Facility

VOIRA Voluntary Operated Individualized Residential Alternative

W

WAT Work Adjustment Training

WIC Women, Infants, and Children

WNY DDSO Western New York Development Disabilities Office

X (There are no acronyms beginning with X at this time.)

Y (There are no acronyms beginning with Y at this time.)

Z (There are no acronyms beginning with Z at this time.)

?- If you have suggestions for the Acronyms List, please contact Lorraine Blum at Parent to Parent of NYS: 716-517-3448 or p2pwny@verizon.net.
Reference for acronyms: www.omr.state.ny.us/journal/hp_acronym.jsp