



***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 – NYCares 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:

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 Childrens Services Initiatives

CDC Centers for Disease Control & Prevention

CDPC Program Consumer Directed Personal Care Program
or

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

ADP Advocacy for Persons with Disabilities
 CR Community Residence
 CSE Committee on Special Education
 CSEA Civil Service Employees Association
 CSP Community Services Plan (formerly CSEP)
 CSS Consolidated Support and Services
 CSW Certified Social Worker

D

DARS Division of Administration & Revenue Support
 DC Developmental Center
 DD Developmental Disabilities
 DDAWNY Developmental Disabilities Alliance of WNY
 DDP Developmental Disabilities Profile
 DDP4 Developmental Disabilities Profile (Request for Services Form)
 DDPC Developmental Disabilities Planning Council
 DDSO Developmental Disabilities Services Office
 DME Durable Medical Equipment
 DNR Do Not Resuscitate
 DOB Date of Birth
 DOB Division of Budget
 DOH Department of Health
 DQA Division of Quality Assurance (OPWDD)
 DSS Department of Social Services
 DTx Day Treatment
 DVE Diagnostic Vocational Education

E

EBT Electronic Benefit Transfer
 ECDC Early Childhood Direction Centers (State Education Department)
 ECDMH Erie County Department of Metal Health
 ECMC Erie County Medical Center
 EHC Elmwood Health Center
 ED Emotionally Disturbed
 EIP Early Prevention Program

EIS Environmental Impact Statement
 EMOD Environmental Modification
 EPSDT Early Periodic Screening & Diagnostic Treatment Program

ED Executive Director
 EO Executive Order

F

FAS Fetal Alcohol Syndrome
 FC Family Care
 FCH Family Care Home
 FET Family Education and Training
 FFC Foster Family Care
 FLSA Fair Labor Standards Act
 FOIL Freedom of Information Law
 FSS Family Support Services
 FTE Full Time Equivalent
 FFY Federal Fiscal Year
 FY Fiscal Year

G

GAAP Generally Accepted Accounting Principles

H

HCBSW Home & Community Based Services Waiver
 HHC Home Health Care
 HHS Health and Human Services
 HIPPA Health Insurance Portability and Accountability Act
 HIV Human Immunodeficiency Virus
 HMO Health Maintenance Organization
 HRC Human Rights Committee
 HSA Health Systems Agency
 HUD Housing and Urban Development

I

IBR Institute for Basic Research in Developmental Disabilities
 ICF Intermediate Care Facility

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

M

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

N

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

Q

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

T

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