## NJ Children's System of Care



Youth and Family Guide

## **Helpful Numbers**

Website: www.performcarenj.org
PerformCare: 1-877-652-7624
My Child's CYBER ID:  (See the "Getting Started" section on page 7 for more information)
In Home Provider:
PerformCare:
Primary Care Provider:
Dentist:
Other Important Numbers:



### Contents

Welcome to PerformCare	4
About us	5
Our mission	5
How we can help you	5
How you can help us	6
Getting information	6
Getting started in the Children's System of Care	7
The System of Care approach	8
Benefits and Services	11
Who can get services?	12
Do I pay for services?	12
What kinds of services are there?	13
Needs Assessment	15
Care Management services	16
Intensive In-Home (IIH) or Intensive In-Community (IIC)	17
Substance Use Treatment Services	17
Support for families/caregivers	18
Youth involvement and peer supports	20
Services not provided by the System of Care	22
Transition to adult supports	23
Member Rights, Quality and Reporting Concerns	24
Rights and responsibilities of youth and their families	25
Our commitment to quality	26
Privacy	31
Health Insurance Portability and Accountability Act (HIPAA)	32
Individual control of health information	33

Information regarding the Notice of Privacy Practices	33
Making amendments	34
Routine use of information	34
Non-routine disclosure of information	35
Information shared within the Department of Children not defined.	n and Families <b>Error! Bookmark</b>
Confidentiality laws and regulations	35
Substance use and HIV/AIDS information	35
The Release of Information Authorization	
Consent to release information for youth ages 14 and	older36
Privacy notice	
Special Circumstances	40
Legal guardianship	41
Step parents	41
Military families	41
DCP&P involved families	42
Homeless young adults (Adolescent Housing Hub)	42

## **SECTION I**

## Welcome to PerformCare



- About us
- Our mission
- How we can help you
- How you can help us

In this section, you will learn about the role of PerformCare, what a System of Care is and how it works for you and your child, and how to access information and services.

#### About us

PerformCare is the single point of access to coordinate care for youth receiving services funded by the NJ Division of Children's System of Care. PerformCare connects young people with the care they need in the most appropriate setting.

PerformCare helps families access the right services for their children. Specifically, PerformCare can help you access publically-funded services for New Jersey children with behavioral, emotional, intellectual, developmental, and/or substance use challenges.

PerformCare has been connecting families to services funded by the NJ Division of Children's System of Care since 2009.

PerformCare is a member of the AmeriHealth Caritas Family of Companies, which provides health care solutions for underserved populations across the nation.

#### Our mission

We help people get care, stay well and build healthy communities.

#### How we can help you

PerformCare can help you figure out the right services or supports for your child and family. These may include services available through your regular health insurance plan, community resources, or public services.

Sometimes it can be hard to tell the difference between what may be "normal" for your child and when you should reach out for extra help. For example, it may be helpful to contact PerformCare if:

- You are struggling to meet the needs of a child or adolescent who has a developmentally disability.
- Your child is refusing to attend school, has repeated lateness or absences, or if you have other concerns about his or her school performance.
- Your child shows physical/verbal aggression, bullies others, or is being bullied.
- You observe family conflict, including youth substance use or refusal to comply with rules.
- Your child has experienced a major loss or change (death, divorce, relocation, etc.) and doesn't seem to be adjusting well.

- Your child experiences a traumatic event, such as a house fire or witnessing violence.
- A friend, teacher, or other trusted adult has expressed concerns about your child.
- You'd like to know more about the types of services available.

#### How you can help us

In order to provide the best care to all families, we need your help. It is important to:

- Let us know if you've moved or your contact information has changed.
- Keep your benefit information updated with your primary health insurance plan. PerformCare is not an alternative to a comprehensive health plan, and taking care of physical health care needs is even more important when a child has a behavioral, developmental, intellectual, or substance use challenge.
- Communicate with us and with the providers we connect you with about your child's strengths, needs, and family situation. This may include:
  - o Making appointments with the providers we connect you with.
  - o Cancelling appointments when you can't make them.
  - o Calling your provider or PerformCare if you have questions.
- Talk with your providers to agree on treatment goals and to make sure you understand the service they are providing.

If you have any questions about your responsibilities or for more information, call us toll free at **1-877-652-7624**. Our Member Services department will help connect you to the right person or resource you need.

#### **Getting information**

#### By telephone

The best way to contact PerformCare is by telephone. You can call 24 hours a day, 7 days a week. We always have trained clinical staff available to assist you.

#### What to expect when you call

When you call PerformCare, our skilled Member Services department staff can help answer most of your questions. In order to do so, we ask for information from you about your child. This information — which includes your name and phone number, your child's name, date of birth, social security number, and other health insurance — allows us to confirm that we are speaking about the right child, gives us information

about how to contact you for follow up, and ensures that we are getting information from the right source. We will ask for this information every time you call.

While almost anyone who cares about a child can call to get general information, usually only the parent or legal guardian is allowed to get specific information about a child or request services. There are also some services that youths may call to access by themselves, such as substance use treatment services.

#### On the Internet

Our website contains the most up-to-date information available, including:

- Contact information.
- Descriptions of services available.
- Fact sheets and frequently asked questions.
- Links to local community resources.
- Application materials.

Our website is <u>www.performcarenj.org</u> and most of the information you will need can be found in the <u>Families</u> section. If you do not have access to the Internet, most of the information is in this handbook, or it can be mailed to you upon request. If you have additional questions, please call us.

#### In other languages and formats

PerformCare has written materials in languages other than English and in other formats for the visually impaired. These materials do not cost you any money. Please call us at **1-877-652-7624** to ask for member materials in another language or format.

If you do not speak English, we have representatives who speak languages other than English. We can also use the Language Line Services to speak to you through an interpreter.

If you are deaf or hard of hearing, our TTY number is **1-866-896-6975.** 

#### Getting started in the Children's System of Care

When you first call PerformCare to access services, we register your child. At this point, we generate a unique number for your child, called a CYBER ID. Any letters we send you will have this number on it, and if you have the CYBER ID number when you call,

it can help us get you the information you need faster. We have provided a spot on the inside front cover of this book to write down your child's CYBER ID.

When your child has complex or overwhelming challenges and multiple services or providers are necessary, it can be difficult to keep track of who is providing services. We have provided space at the front and back of this book where you can write down information about your child's care providers. If you are not sure if a provider is still connected with your child's care or have lost the provider's contact information, you can call PerformCare to check.

#### The System of Care approach

Parents/legal guardians of youth who use services are often interested in knowing how the "system" works. "System" refers to the different services and types of care in place to help parents/guardians care for their youth. It is important for you to know:

- Who makes up the children's "system" of care.
- What the system offers.
- How the services, supports, and advocacy offered helps your youth and family.

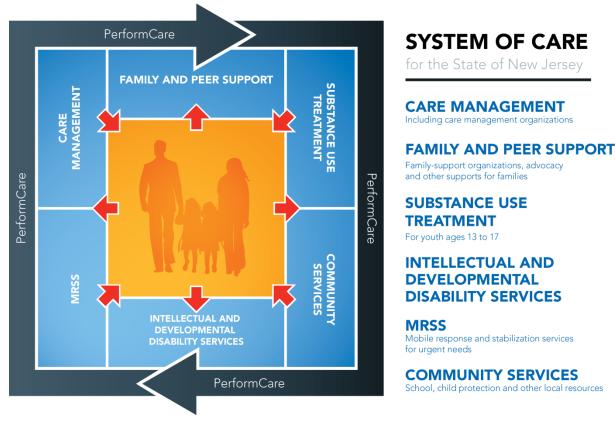
When you call PerformCare to access a service or support, your child becomes part of New Jersey's Children's System of Care (CSOC). This is the name of the *division* that funds the services. But the actual *system* of care is a special approach to how, when, and where services and supports are offered.

The System of Care approach to service delivery for children began in the 1990s as communities were looking for ways to improve the well-being of children with serious emotional and behavioral disorders. At that time, there were almost no community-based treatment options for families, and private insurance resources were limited. Out-of-home treatment often required giving up custody of children to child protective services. Over the past two decades, the System of Care approach has been tested and refined in communities around the country, and expanded to include very young children, children in state custody, and children in detention.

The New Jersey Children's System of Care began as a federal grant program in 1999, and expanded to provide services in every county by 2006. The New Jersey Children's System of Care has long provided supports to youth with behavioral health challenges both in the community, and those involved with child protective services. In 2013, it also began serving children with developmental and intellectual disabilities and their families, and providing coordinated access to substance use treatment services for certain youth.

The Children's System of Care Initiative adopted by the New Jersey Department of Children and Families was developed through the joint efforts of families, providers, advocates, and other stakeholders across the state. It is based on basic principles designed to create a children's service delivery system that:

- Increases access to services and supports.
- Empowers parents and guardians in seeking care and positively impacting the system to improve it.
- Assures the ability of families to share their ideas, concerns, needs, and suggestions.
- Enhances the integrity and quality of family and community life.



Through an organized network of services and supports, the New Jersey Division of Children's System of Care is committed to providing emotional /behavioral health, intellectual/ developmental disability, and substance use treatment services that are:

 Clinically appropriate and accessible, without regard to income, private health insurance or eligibility for NJ FamilyCare or other health benefits programs.

- 2. Individualized, reflecting a continuum of services and/or supports, both formal and informal, based on the unique strengths of each youth and his or her family.
- 3. Provided in the least restrictive, most natural setting appropriate to meet the needs of the youth and his or her family.
- 4. Family-driven, with families engaged as active participants at all levels of planning, organization, and service delivery.
- 5. Community-based, coordinated, and integrated at the community level, with the focus of services, as well as management and decision-making responsibility, resting at the community level.
- 6. Culturally competent, with agencies, programs, services, and supports that are responsive to the cultural, racial, and ethnic differences of the populations they serve.
- 7. Protective of the rights of youth and their families.

## **SECTION II**

### **Benefits and Services**



- Who can receive services
- Types of available services
- Services not covered
- The role of other health insurance

In this section, you will learn about the benefits that PerformCare offers, how to access those benefits and how services are provided if you have other types of insurance.

#### Who can get services?

You can access services for youth up to age 21 (up to 21st birthday) who reside in New Jersey and meet specific eligibility criteria for each service type:

- Youth with emotional/behavioral disorders must be in need of services that are not typically provided through primary health insurance (typical services include outpatient individual therapy or partial hospitalization) and must meet the specific eligibility rules for each service type.
- Youth with intellectual/developmental disabilities must first be determined "Developmental Disability (DD) eligible" in order to receive services. The application is available on our website for youth up to their 18th birthday. If you don't have access to the Internet, we can mail you an application. Youth who were determined DD eligible by the NJ Division of Developmental Disabilities do not have to reapply in order to receive services in the Children' System of Care.
- Certain youth with substance use needs up to the age of 18 who have no insurance coverage for substance use treatment or have exhausted existing coverage.
- Certain homeless youth up to age 22.

#### Do I pay for services?

There is no charge for calling PerformCare. Most of the services we authorize are provided at no cost to you.

The services PerformCare connects you to are authorized without regard to income or private health insurance coverage. However, some services require that private health insurance be exhausted first. PerformCare will ask for your other health coverage information to provide the best options for your child's care.

#### NJ FamilyCare eligibility

Many services are covered by NJ FamilyCare (Medicaid). When you are connected to a provider through PerformCare you may be required to apply for NJ FamilyCare in order to continue receiving services. There are special limited NJ FamilyCare options available to certain children that are not eligible for a standard NJ FamilyCare plan, so allowing the provider to complete the application with you will help us best meet the needs of your child.

If your child is already covered by NJ FamilyCare, please let us know when you call.

#### Other health insurance

If you have health insurance coverage for your child through your employer or another non-Medicaid plan, you can still access services and resources through PerformCare if needed. PerformCare helps connect families to services that are not typically available through a standard health plan. Many children, however, do benefit from traditional health and mental health services available through health insurance. System of Care services are designed for youth whose complex needs that cannot be addressed through typical services. For instance:

- A youth who has been in outpatient counseling for depression and has had multiple trips to the emergency room for suicidal thoughts and doesn't seem to be getting any better.
- A child with mobility impairments requiring a ramp or lift at his or her home that is not covered by the primary health plan.

The Children's System of Care does not replace the services available to you through a traditional health insurance plan. Instead, it may be able to offer some publically-funded services and supports.

#### What kinds of services are there?

The System of Care includes a broad range of services to support the needs of children with complex challenges. Below are descriptions of the most commonly available services.

It is important to know that each of these services is designed to meet very specific sets of needs. As a parent, you likely have a good idea of what services your child may benefit from, but your child will need to meet certain eligibility criteria, as well as other requirements, to be matched to a particular service.

The recommendations for services are made through detailed information gathered about your child and family needs, whether provided to our clinicians over the phone, to a community-based provider, or care manager. We are here to help you navigate the services available, and provide the best supports to your child.

Generally speaking, these services fall into one or more of the following categories:

- Urgent and emergency crisis response and stabilization.
- Case Management.
- In-home services (intensive in home/intensive in community).
- Substance use treatment services.

- Out-of-home treatment.
- Support for families and caregivers.
- Youth involvement and peer support.

#### **Emergency services: Behavioral Health**

A behavioral emergency is any serious behavior on the part of your child that, if not dealt with right away, could lead to your child being harmed or harming someone else. If you have an emergency situation involving your child, get help immediately!

For medical emergencies and any immediately life-threatening emergency, always call 9-1-1 or go to the emergency room first.

If you call PerformCare in an emergency, you will be connected directly with a trained clinician. That person will ask questions to best determine how to help you. Depending on the crisis, you may be referred to your local hospital psychiatric screening center or, in a serious emergency, to 9-1-1. If your child is screened at an emergency room or is hospitalized, you or the child's treatment team can request other supports from PerformCare to help when the immediate emergency is over.

Examples of emergencies include:

- Threatening self or others with a weapon capable of causing harm (such as a knife or gun).
- Current active violence against another person, such as hitting or being hit by someone, or witnessing violence between other individuals.
- Self-inflicted injury requiring medical attention.
- High-risk behavior, such as running into heavy traffic.

There are 2 key types of services available to children experiencing a behavioral health emergency, and you do <u>not</u> need to call PerformCare to access them:

- Psychiatric Emergency Screening Centers are based in or alongside hospital emergency rooms, youth with an immediate danger to themselves or others should be transported to a center for screening for urgent services or inpatient psychiatric hospitalization.
- **2.** Children's Crisis Intervention Services (CCIS) a network of regional short-term psychiatric hospital inpatient treatment units that serve children ages 5 to 17 who have been determined to be an immediate risk to self or others.

Urgent care for behavioral health crisis: Mobile Response

In a true emergency, time is of the essence and police or a hospital may be required. However, in urgent behavioral situations (where a persons' immediate safety is not at risk but a child's behavior is escalating beyond a parent's or caregiver's ability to manage it) we are able to connect families to their local Mobile Response provider. Mobile Response will respond to the crisis, in person, within one hour from your call to us. Typically, this is in the home, but if the crisis occurs outside the home and a parent is able to be present, Mobile Response may be available to assist. With the input of the family and, when possible, the youth, Mobile Response will help address the immediate crisis, identify family strengths and needs, and work to develop a plan to address the cause of the behavioral crisis.

If you are currently involved with a care management organization (CMO), PerformCare will remind you to contact your care manager who will call you back to help support you through your emergency.

#### **Needs Assessment**

Sometimes PerformCare or our providers need more information than can be collected over the phone in order to make an accurate assessment of your child's needs and the most appropriate resources or services. In this case, PerformCare will authorize a Needs Assessment, also known as a BPS (BioPsychoSocial). This means a licensed clinician will meet with you in person to collect more information.

These clinicians are independent providers, practicing either alone or as an employee of a local agency. They do not work for PerformCare.

If you are told that your youth requires an assessment, here's what to expect:

- Within 3 calendar days of your call to PerformCare, a licensed clinician will call to schedule an appointment to discuss your youth's and family's needs.
- Within 1 week after you set the appointment, the clinician will meet with you to complete the assessment and make recommendations regarding what supports best fit your needs. This assessment is sent to PerformCare.
- Within 5 business days from the date the assessment is received, PerformCare will review it to see what clinically appropriate resources may be available based on need.
- Within 3 business days following the review by PerformCare, any provider or providers authorized by PerformCare will contact you to arrange for services.
- There is information in this guide that tells you how to contact us if you disagree with a decision and would like to file a reconsideration or appeal.

In some cases, your child might need an assessment done by someone with extra experience or qualifications, such as in substance use or developmental disabilities. Because there are fewer clinicians with these types of qualifications, it may take a little longer to set up an appointment than described above.

You do not pay out of pocket for a Needs Assessment authorized by PerformCare. However, we cannot authorize a Needs Assessment at the request of another entity such as a school. Also, only two Needs Assessments can be authorized in any 12-month period.

#### Care Management services

A youth with complex needs — whether based on multiple service providers, out-of-home treatment, or another combination of factors — can receive coordinated care by an individual who helps the youth and family develop an integrated service plan, and monitors service needs. This is called "care management," and there are several types of care management available. Because a case manager's primary job is to help coordinate all the different services and resources needed, a child may only have one type of case management at a time.

Care management organizations (CMOs): These county-based, nonprofit organizations are responsible for face-to-face care management and comprehensive service planning for youth and their families with intense and/or complex needs. They coordinate the Child/Family Team meetings, and implement Individual Service Plans (ISP) for each youth and his or her family. The CMO provides a single point of accountability for the organization, the delivery of services and the supports needed to maintain stability for each youth, utilizing a wraparound approach to planning.

**Other Care Management services:** Some of the other services offered in the Children's System of Care have case management integrated into the service delivery model. That means a youth receiving one of these services would not be appropriate to receive additional care management through a CMO.

**Mobile Response**: Youth who receive ongoing support past the initial 72-hour crisis stabilization period may receive care management as a component of the 8-week Stabilization Services.

**Multi-systemic therapy and functional family therapy**: These 6-month, intensive family therapy models are often offered to children involved with, or at risk of involvement with, the juvenile justice system.

#### Intensive In-Home (IIH) or Intensive In-Community (IIC)

While traditional therapies are typically provided at the health care provider's office location, intensive in-community/in-home services are provided in the child's home or at another location in the community that makes sense to both the family needs and the goals of the service. IIH and IIC covers a variety of services geared to assist youth with challenging behaviors that may impact their ability to remain at home.

#### **Substance Use Treatment Services**

If your child is struggling and you suspect or know that drugs or alcohol are involved, appropriate substance use treatment services can help your child get back on track.

Your best resource for accessing treatment services is through your health insurance (private insurance or NJ Family Care). Your health insurance carrier can explain the kind of benefits available.

If you and your child are enrolled in a CMO, or involved with the Division of Child Protection & Permanency (DCP&P), speak to your care manager or case worker about additional treatment services that may be available.

PerformCare is able to refer and authorize substance use treatment services for a limited pool of youth ages 13 up to their 18th birthday. Appropriate assessment is the first step in obtaining the right treatment. Youth authorized for a Needs Assessment through PerformCare are able to receive a substance use screening as part of the assessment, when indicated.

PerformCare utilizes the ASAM (American Society of Addiction Medicine) criteria for making clinical decisions about what type of service is most appropriate. These decisions are made by licensed clinical alcohol and drug counselors (LCADCs) with appropriate specialized training.

#### Out-of-home treatment

While the goal of the system of care is to provide the services and supports necessary to keep a child at home and connected to their school and community, sometimes this is not possible due to the safety of the child, the community, or the unique challenges of the child or family. Recognizing that your child may require care beyond your own abilities can be overwhelming, and the decision to do so is never made lightly. Whenever possible, the Children's System of Care works to provide supports that will enable a child to remain at home.

If your child requires out-of-home treatment, PerformCare will ensure you are connected to a care manager, and will work with your CMO to ensure identification of the most home-like and least restrictive program that can meet your child's needs.

Out-of-home treatment settings are available in every county in New Jersey, and represent a variety of intensities of care, from treatment homes that provide specially monitored care in the homes of experienced, trained, and supervised caregivers, to small community residences of about 5 young people each, to larger specialized medical and psychiatric facilities.

Depending on your child's needs, you may be connected with multiple potential out-of-home providers, and are encouraged to use initial meetings/interviews to ask questions, gather information, and select the provider you feel most comfortable with.

When a child does go into out-of-home care or treatment, PerformCare and your care manager monitor the progress of your child, from admission through ongoing care, and ensure that the discharge plan when the child returns home adequately reconnects the child to the community and appropriate services. Family participation during the entire episode of out-of-home treatment is an important part of successful transition home.

We know that children are almost always better off when cared for by their own families, and are dedicated to supporting youth in their own homes whenever possible.

#### Support for families/caregivers

#### **Family Support Organizations**

Family Support Organizations (FSO's) are nonprofit, county-based organizations run by families of children with emotional and behavioral challenges. FSOs work collaboratively with care managers, Mobile Response, PerformCare, state agencies, and

other providers to ensure that the system is responsive to the needs of families and youth. The FSO provides peer support, education, advocacy, and system feedback to families. Additionally, families of youth referred to CMOs may choose to have a Family Partner from the local FSO as part of their Child & Family Team.

#### **Family support services**

If determined eligible for developmental disability services for your child AND if you meet the criteria for Family Support Services, the services described below may be provided, based on availability and appropriateness to your child's and family's needs.

Assistive technology is designed to increase the functional skills of a youth with a developmental disability, and enhance his or her ability to live successfully in the community. An assistive device is an item that is used to increase, maintain, or improve functional capabilities of the youth, and is not solely therapeutic. Vehicle and home (environmental) modifications are also included in this category. It must be an item not covered by medical insurance, and a prescription from a medical professional is required.

Respite is intended to provide temporary relief for the primary caregiver from the demands of caring for an individual with disabilities during the times when the caregiver would normally be available to provide care. The service relieves family members from care on a temporary basis for short periods of time. The word respite means "break" or "relief." Respite care services are designed to offer families the opportunity for a break from care giving responsibilities. Respite also provides a positive experience for the individual receiving care. Respite also allows parents time to engage in activities they find relaxing, entertaining, or restful, while a trained respite provider cares for their child.

#### Summer camp financial assistance

The continuation of predictable routines and opportunities for structured group interaction are valuable to many youth, including youth with disabilities and other challenges. Recognizing this value, the Children's System of Care offers limited tuition support for eligible youth to attend summer camp. Camp can be provided at either a specialized camp or a mainstream camp, as long as the camp becomes qualified as a camp provider through CSOC. Instructions for becoming a qualified camp are available on the PerformCare website.

Summer camp tuition support is based on available resources in a given fiscal year. Families/caregivers are encouraged to explore all avenues for funding summer camp

tuition, such as contacting local recreation departments and civic groups, and asking camp providers about the availability of scholarships.

Children, youth and young adults (under age 21) may be eligible for CSOC financial support toward summer camp tuition if:

- They reside in their own home with an uncompensated caregiver, AND
- They are deemed eligible for CSOC Developmental Disability (DD) Services.

CSOC financial support toward summer camp tuition **does not** cover the following costs: camp registration, deposit, transportation to and from camp, or trips taken during camp.

Summer camps may either choose to require the family/caregiver to pay all costs in advance or reduce the cost by the aid amount. If the camp requires you to pre-pay the full cost in advance, reimbursement for the aid amount will be provided to you by the camp after the summer camp session has closed.

#### Mom2Mom

When you are taking care of a child with challenges, it can be hard to remember to take care of yourself, as well. Mom2Mom provides telephone peer support to parents raising a child with any kind of disability. The person on the phone is another parent who has faced similar challenges in parenting a child or children with disabilities. Mom2Mom peers can provide an understanding ear, as well as help identify and connect you to local resources, and will follow up with you and help you problem solve challenges. You can call Mom2Mom at **1-877-914-MOM2**.

#### Youth involvement and peer supports

The major role of youth's voices in making sure they get the right care and treatment, as well as in giving feedback on the effectiveness of services and policies, is <u>very</u> important and a key value of systems of care. New Jersey led the way in involving young people in the development of our system of care, and youth engagement is one of the things that make our service delivery effective.

Youth should be involved in setting goals and creating their own plans, as much as possible. For youth involved in CMOs, there is a helpful guide about treatment planning called "Your Life, Your Future: A Youth Guide to Wraparound Services." It is available on the PerformCare website in the Youth section.

There are a number of ways for youth, particularly teens and young adults, to get involved with peers who face similar challenges as both peer support and local and

statewide advocacy. Examples of some of the core opportunities for youth to get involved are described below.

#### **Youth Partnerships**

Located throughout the state, Youth Partnerships provide a variety of local events and opportunities for teens and young adults to advocate for their own mental health and that of their peers. These meetings are held weekly to monthly, depending on area. For more information, contact your local Family Support Organization (FSO). The FSO contact information is available on our website.

Many Youth Partnerships are members of Youth MOVE (<u>www.youthmove.us</u>), a national organization dedicated to empowering youth involved in systems of care to be effective voices for change.

#### **Youth Leadership Project**

Young advocates with developmental disabilities are encouraged to become powerful advocates for personal and systems change. The NJ Council on Developmental Disabilities provides training in advocacy, including public speaking skills, for interested youth and opportunities to network and engage in advocacy statewide. Contact the Council at **1-609-292-3745** (TDD: **1-609-777-3238**) for more information.

#### **Youth Advisory Boards**

The New Jersey Children's System of Care serves youth of many different experiences and backgrounds, including youth who are or were involved in the foster care system. Youth with experience in foster care, out-of-home treatment, or other involvement with DCP&P are encouraged to provide their feedback on local and system improvements by getting involved in their local Youth Advisory Boards. The Youth Advisory Boards collaborate with the Department of Children and Families, Office of Adolescent Services in making recommendations for change. More information is available online at <a href="http://socialwork.rutgers.edu/InstituteForFamilies/officeofchildwelfareinitiatives/TFY/Projects/statewideYAB.aspx">http://socialwork.rutgers.edu/InstituteForFamilies/officeofchildwelfareinitiatives/TFY/Projects/statewideYAB.aspx</a>.

#### 2nd Floor – New Jersey's Youth Helpline

The New Jersey Statewide youth helpline, 2NDFLOOR, is available 24 hours a day, 7 days a week to youth and young adults ages 10-24 to help find solutions to the problems they face at home, school, or play.

Youth can either call the helpline, **1-888-222-2228**, or access the interactive website <u>www.2NDFLOOR.org</u>. The helpline is supervised at all times by a mental health

professional. Youth are provided with relevant and appropriate links to information and services to address their social, emotional, and physical needs. Calls to the 2NDFLOOR youth helpline are anonymous and confidential, except in life-threatening situations.

#### Other opportunities

More resources, information, and links for youth can be found in the "Youth" section of our website, including how to access peer recovery meetings for substance use challenges, and other youth-driven and youth-focused resources available throughout the state and on the Internet.

Youth are also encouraged to get involved locally. Check if your child's service providers have internal Youth Boards or other formal or informal ways of involving youth in service design and delivery.

#### Services not provided by the System of Care

#### **Outpatient services**

Outpatient services are individual or group mental health treatment services provided at a providers office, clinic, or other health care facility. This may include individual or family therapy. Outpatient services are often provided through the behavioral health coverage of your medical plan, if you have private insurance. These services may have a fee, copay, or cost sharing associated with them.

If our telephone or in-person assessment indicates that your child may benefit from counseling at a local outpatient center, you will be provided with a list of selected outpatient providers in your area. A searchable directory of outpatient providers is also available on our website. If you have private insurance, we will ask you to contact your insurance company to see what behavioral health outpatient services are offered.

#### School and education services

The Children's System of Care does not provide school/educational services that would otherwise be covered under the Individual with Disabilities in Education Act (IDEA), or similar public education law, such as occupational/speech therapy or private therapeutic schools. Services and supports covered under public education mandates, as well as services that enable a child to benefit from education, must be accessed through the local school district. This often happens through an Individualized Education Plan or 504 plan.

#### **Experimental or investigational treatments**

Services provided through the NJ Children's System of Care are funded in large part by public taxpayer money. Both specific limits on use and purpose of the funds, as well as an obligation to be responsible stewards of public money, limit the scope of services available. Unless state law dictates otherwise, families cannot access or request payment, reimbursement, or use providers of services that are considered experimental or investigational in nature, including medication and treatments not approved by federal and/or state regulators.

#### Transition to adult supports

The NJ Children's System of Care serves youth until their 21st birthday, with a few exceptions. While services and interventions are designed to be delivered early and to maximize the strengths and abilities of the youth and families we serve, we recognize that a substantial number of the youth we serve will require ongoing supports as adults.

Your service providers should provide treatment/supports with an honest discussion and constant attention to preparing for transition/discharge, whether this is changing to a different type of service or "aging out" into adult services.

If you receive case management or care management, preparing for discharge and transition should be an ongoing conversation, and a smooth transition identifies the right combination of ongoing services, new supports, resources, and informal/community connections that will help your child and family succeed.

## **SECTION III**

# Member Rights, Quality and Reporting Concerns



- Youth and family rights
- Notifying you of changes to your care
- Our commitment to quality
- Concerns, complaints or appeals

In this section, you will learn about your rights, how we communicate with you when your benefits change and what to do if you have a complaint or concern.

#### Rights and responsibilities of youth and their families

Your youth is entitled to certain rights when you sign him/her up for care. As a parent/legal guardian, you also have certain rights.

It is the policy of PerformCare and the Division of Children's System of Care (CSOC) that youth and their families have the right to:

- Be treated with respect, dignity, and recognition with regard to privacy and cultural sensitivity.
- Receive information about all system partners, and the processes for conducting business.
- Request and receive information regarding their families' care, and clinical records.
- Receive general information about all system partners, if available.
- Expect that all information regarding current or previous services be kept confidential, to the extent allowed by law.
- Refuse to disclose information to the agency or provider, to the extent allowed by law.
- Expect that no identifying information will be released without the valid written consent of that youth and/or parent/legal guardian on file. This is a right protected by law.
- Be informed of services, benefits, and how to access care.
- Choose and/or change provider(s).
- Receive care in a timely manner. Timely manner applies to best practices and timelines established within CSOC. These timelines are part of the information available to all youth and their families.
- Participate in a candid discussion with their system partner(s) regarding appropriate options necessary to achieve their family vision, regardless of cost or benefit coverage.
- Openly communicate complaints, grievances, or appeals about any system partner/provider regarding any issue without fear of retaliation or of losing their benefits.
- Timely resolution of complaints, grievances, and appeals.
- Have grievances and appeals reviewed by a party not involved in a previous decision regarding the same issue.
- Continue to receive support and assistance until your complaint is resolved.
- Request a NJ FamilyCare Fair Hearing.

#### What are notification rights?

You have the right to know when your youth's service will change or end. When you receive an authorization letter from PerformCare for services, it will indicate the start and end date of the authorization. The service will end on the date noted in the letter unless something happens that changes the end date. This happens when:

- Your child becomes 21 years old, or otherwise passes the age cap for a certain services or support.
- You receive a letter with a new authorization end date.
- You, as the parent/legal guardian of the youth (and/or your youth, if applicable) give notice that you do not want the service.
- Your youth is admitted somewhere that makes him/her ineligible for other services.
- Your youth receives Medicaid from another state.

Your individual provider(s) are responsible for notifying you and verifying end dates of services, especially if they are discharging you from their service or support.

#### Our commitment to quality

At PerformCare, we are committed to ensuring that children, youth and young adults receive the care they need, and we are always looking for new ways to improve our services. Our Quality Improvement (QI) program systematically monitors and evaluates the quality of clinical care and service delivery by PerformCare staff, as well as our service providers. We use proven approaches to check how we are doing and determine how we can improve. Through the QI program, we:

- Watch for things that show a need for improvement.
- Perform service delivery studies when we see they are needed.
- Monitor the quality of care and services given by providers.
- Use family feedback to improve our services.

In this section, you will find information about what you can do if you have a concern about the services you have requested or are accessing through PerformCare.

#### **Complaints and concerns**

PerformCare is responsible for resolving complaints for the Division of Children's System of Care (CSOC). When you have a concern about the quality of services in the system, you have the right to file a complaint. Your youth's care will not be affected by your complaint.

Your first step is to address the complaint with the person or agency with which you have the concern. If you are not satisfied with the result after going through their review process, you may submit a complaint, request a Reconsideration, or file an appeal.

#### **Complaints**

You may have a complaint if you are dissatisfied by a component of the care you have received, such as the quality of a service, timeliness, or provider performance. If you have a complaint about any service provider PerformCare has authorized or about the treatment you have received while on the phone with us, you may file a complaint at any time during a call.

#### What if I have a concern about a provider?

If you have a concern about the quality of services from a service provider we have authorized, you have the right to file a complaint. Please know that your child's care will not be affected by your complaint. Your first step should be to address the complaint with the person or agency with which you have the concern. If you continue to have a concern about the care of your child, you can call PerformCare to make a complaint, and we will assist you and the provider in reaching a resolution.

If you suspect your provider is engaging in fraudulent activity around payments or service delivery, you should let us know right away. Examples of fraud/abuse include:

- Giving you treatment or services that you don't need.
- Agreeing to provide a service before it has been authorized by PerformCare.
- Asking you to sign off on participating in services or visits that have not yet occurred.
- Offering you gifts or money to receive treatment or services.
- Physical, emotional, or sexual abuse by staff.

#### What if I disagree with a decision about my child's services?

If you have a concern about a decision made by PerformCare or a service provider authorized by PerformCare, such as a change in the type or amount of services or a denial or termination of services, you may be eligible to request further review of the situation. PerformCare staff is available to assist you in this process. The type of dispute resolution to which a youth or family is entitled varies depending upon the services for which the youth or family is eligible.

Complaints are generally resolved within 5 business days, and you will receive written notification of the complaint resolution.

You can submit a complaint over the phone by calling us at **1-877-652-7624** or in writing:

PerformCare 300 Horizon Center Drive, Suite 306 Robbinsville, NJ 08691

#### Reconsiderations

Reconsideration is the simplest and quickest way to communicate a concern and request a change to a decision made by PerformCare or a provider about a service you are receiving that we have authorized. Reconsideration is a process that is designed to help you resolve issues more quickly than the Medicaid fair hearing process, the NJ FamilyCare grievance review process, or the Division of Children's System of Care appeal process. The Reconsideration process involves a review of the existing information we have, and is conducted by the clinical management to determine whether to maintain the same level of care determinations and service authorization decisions or overturn the initial decision.

While a Reconsideration is under review, your child will receive the same services authorized prior to the request, and can continue to use those services until you are notified of the decision. PerformCare will attempt to reach a decision within 5 business days of the request. Reconsiderations of services are reviewed by the clinical management and/or medical director.

PerformCare will notify you within 48 hours of making the decision.

#### **Appeals**

The appeals process is a formal review that may involve a telephone or in-person hearing, available to a youth and family where a request for services has been denied, terminated, reduced, or if you disagree with the type of service authorized. The actual review is conducted by either Medicaid or the Division of Children's System of Care. PerformCare provides information and assistance for the appeal, and will simultaneously initiate the Reconsideration process if you haven't already requested it.

You may request an appeal of a prior reconsideration or ask for an appeal right away. If you have not already asked for reconsideration, PerformCare will start the reconsideration process at the same time the appeal is begun.

If your child is on a NJ FamilyCare health insurance plan, the appeals process is through a Medicaid fair hearing request or grievance review, depending on the plan.

Your fair hearing /grievance request must be in writing, and must be submitted within 20 days of when you were notified of the decision you did not agree with.

Send requests for a fair hearing or grievance review to the address or fax number below. If you have questions about the process, you can contact the Medicaid Office of Legal and Regulatory Liaison at **1-609-588-2655**.

DHS—Division of Medical Assistance and Health Services

Fair Hearing Unit P.O. Box 712 Trenton, NJ 08625 Fax: 1-609.588.2435

If your child is not receiving NJ FamilyCare or any other Medicaid-administered health benefits program, you may request an appeal by the Division of Children's System of Care.

A request for an appeal must be in writing and made within 30 days of receiving written notice of the decision you disagree with (initial service authorization or result of the reconsideration/complaint).

Your request should include:

- The name and address of both the person filing the appeal and the child receiving services.
- A brief statement of the matter under appeal.
- Any information you have or know of that supports the request; and
- A list of all agencies and/or people involved in the dispute.

If you know the law, policy, or rule that applies to the situation that you think is being inappropriately applied, please include that, as well.

Mail the request to:

Director, Division of Children's System of Care P.O. Box 717 Trenton, NJ 08625-0717

The Division of Children's System of Care has 30 days from when it receives the letter to notify you of when the review will take place and what type of review it will be (record review, telephone, or in person). You must be notified at least 5 days before the date of the review. If you are unable to attend the in-person or telephone review, you must let them know or your appeal won't be considered.

It can take up to 60 days from the time you submit the written appeal until a decision is made by the state. After the decision is made, it may take up to an additional 30 days to receive written notice of the decision that was made. Decisions made by appeal to the state are final. There is no higher level review.

## **SECTION IV**

## Privacy



- What information is protected?
- Why is privacy a concern?
- Rules about substance use information
- Our privacy notice

In this section, you will learn about our commitment to the privacy and security of your personal information, including how and when we disclose it.

#### Health Insurance Portability and Accountability Act (HIPAA)

#### What is HIPAA?

HIPAA is a federal law. The law's full title is Health Insurance Portability and Accountability Act of 1996. The primary goal of the law is to help employees take their health benefits with them upon a move from one employer to another. The law also includes a provision with the goal of improving:

- Efficiency of the health care system by encouraging the use of electronic information systems.
- Privacy and security protections for individually identifiable health information.

#### What is "protected health information"?

HIPAA's privacy regulations require protection of individually identifiable health information. The regulations define "protected health information" as information that relates to the:

- Past, present, or future physical or mental health or condition of an individual.
- Provision of health care to an individual.
- Past, present, or future payment for the provision of health care to an individual.

Protection applies to information collected from the individual or received or created by a health care provider, health plan, health care clearinghouse, or employer, and is maintained or transmitted in any form or medium.

#### What information must be protected?

A wide range of information is considered personal, and therefore protected, health information. This includes but is not limited to:

- The fact that someone received treatment.
- Claims information.
- Clinical information.
- Demographic information in the context of health care.

There is no distinction between clinical and other types of information. All are protected under the law.

#### Why all this concern about privacy?

In the age of electronic databases, privacy is an increasing concern for many people. The protections provided in the privacy rule have 3 goals:

- To give individuals greater control of their personal health information.
- To limit what others can do with protected health information.
- To safeguard individually identifiable health information.

Knowing that personal health information is protected should increase trust between individuals and those who provide and pay for their care.

#### Individual control of health information

HIPAA gives individuals rights that increase their ability to control access to their protected health information. All individuals have a right to:

- Obtain a Notice of Privacy Practices.
- Inspect or receive a copy of information that health plans and providers use for making decisions about them.
- Know who has seen their health information for non-routine purposes.
- Request confidential communication of their protected health information.
- Give explicit permission for use of their information for purposes other than treatment, payment, and health care operations.

#### Information regarding the Notice of Privacy Practices

A Notice of Privacy Practices must be provided to tell individuals what information is collected about them and how that information is used. This notice is made available to families for review on our website or by telephone request for a mailed copy at any time.

Information regarding CYBER: the Designated Record Set

Individuals have the right to inspect or copy the information used to make decisions about them. This information, called the Designated Record Set, includes:

- Enrollment.
- Payment.
- Claims adjudication.
- Case or medical management records.
- Any other records used for making decisions about the individual.

Records held by PerformCare and other business associates of DCF/CSOC entities are considered part of the Designated Record Set. The individual has the right to inspect the entire Designated Record Set pertaining to themselves or their child or any protected

health information within the Designated Record Set. PerformCare will only release copies of the following items from the Designated Record Set:

- Copy of first assessment and/or service plan.
- Copy of most recent assessment and/or service plan.
- Evidence of eligibility for service, if conducted by PerformCare.

Requests for other data must be obtained from the service provider directly.

#### Making amendments

Families may believe that there are errors in the information in their Designated Record Set. If so, the family has the right to request an amendment so that additional information is included in the record. If treatment was or will be made based upon such a request, everyone who might need to know about it will be notified. This may include insurance companies or providers that treat the youth.

Either the youth (age 14 or older) or the parent/guardian can request an amendment. There is no form required, but the request must be in writing to PerformCare and include enough information to document the reason why the record needs to be amended. PerformCare will make a decision within 60 days of receiving the written request.

PerformCare can only amend records created by our staff, such as information obtained during registration or while talking to our clinical staff. Requests to amend information created by a provider, such as a CMO, must be submitted to that provider.

#### Routine use of information

Although system partners have individual information about the youth they serve as part of the Children's System of Care, they are not free to use it for any purposes they choose. That information may only be used to conduct routine activities, payment, and health care operations, such as:

- Coordinating care between providers or between a provider and a health plan.
- Submitting or paying claims.
- Reviewing utilization patterns.
- Improving clinical services.

#### Non-routine disclosure of information

If the protected health information of a youth is shared for any reason other than conducting routine activities, the agency sharing the information must:

- Obtain an individual Release of Information Authorization (unless required by law or regulation).
- Record the disclosure.
- Be prepared to provide an accounting of such disclosures, if asked.

Examples of non-routine disclosure include:

- Collecting data for marketing, fundraising, or research purposes.
- Releasing information to employers for employment-related decisions.
- Reporting suspected child or elder abuse or neglect.
- Responding to a subpoena or other legal request.

If a disclosure is required by law or regulation, a release is not needed but the disclosure must still be recorded.

#### Confidentiality laws and regulations

It is a requirement that PerformCare adhere to all applicable confidentiality and release-of-information laws and regulations. The following are some of the key laws and regulations that protect your information. Records are protected under:

- Federal (42 CFR Part 2).
- Federal HIPAA (42 U.S.C. 1301 et seq., 45 CFR 160 & 164).
- State statutes (N.J.S.A. 30:4-24.3, 9:6-8.10a, and 9:6-8.40).
- State Regulations (N.J.A.C. 10:37-6.13 et seq.).

#### Substance use and HIV/AIDS information

To release substance use and/or HIV/AIDS related information, there are specific requirements, including that the individual requesting the release of information must state the purpose of the disclosure.

PerformCare considers the privacy of your information as a central component of providing quality services to children, youth, and families. It is important for family members to be aware that substance use treatment services are covered under even stricter privacy rules than behavioral health and general health rules. Youth seeking substance use treatment services must consent on their own to treatment and to release

of records. Parents may not access the substance use treatment portion of the record without their child's consent, nor may they sign on behalf of their child.

#### The Release of Information Authorization

Except when information is used for routine purposes, a Release of Information Authorization must be obtained from the parent/legal guardian and/or youth where applicable. This release must include:

- A description of the information that will be used or shared.
- With whom the information will be shared and for what purpose.
- When or why the release will expire.
- A statement that the release may be revoked at any time and that care will not be denied upon refusal to provide a Release of Information Authorization.

While any written statement that includes the above information can be used to request a release, PerformCare makes the most up-to-date version of releases available on our website for use by parents and providers, and these forms can also be requested by telephone.

There is a separate Release of Information form for individuals seeking substance use treatment services that meets the specific requirements of federal law for this service.

#### Consent to release information for youth ages 14 and older

Where a youth at least 14 years of age or older is receiving services provided through CSOC, written authorization by the youth is required to release information to a parent/legal guardian or third party. If more than one person in a family is receiving services provided through CSOC, any release of information is prohibited without written authorization by each family member who is at least 14 years of age or older. Absent a written authorization of each family member 14 years of age or older, a provider shall not disclose any information received from any family member.

#### **Privacy notice**

#### Privacy practices for protected health information: A notice to our members

This notice describes how medical information about you may be used and disclosed and how you can get access to this information. Please review it carefully.

#### I. Who is PerformCare?

PerformCare is the organization responsible for providing access to care for publically funded services for children and youth with behavioral health, intellectual/developmental disability, and substance use treatment needs within the New Jersey Children's System of Care (CSOC).

#### II. What is Protected Health Information?

"Protected Health Information" or "PHI" is any information, whether oral or recorded in any form or medium; (i) that relates to the past, present, or future physical or mental condition of an individual; the provision of health care to an individual; or the past, present, or future payment for the provision of health care to an individual, and (ii) that identifies the individual or with respect to which there is a reasonable basis to believe the information can be used to identify the individual, and shall have the meaning given to such term under HIPAA and the HIPAA Privacy Regulations, including, but not limited to, 45 CFR §164.501.

#### III. How PerformCare uses and discloses your health information

PerformCare provides a broad range of behavioral health services through a wide variety of behavioral health, developmental disability, and substance use treatment programs. If PerformCare manages care for you, PerformCare may use your protected health information and disclose it to providers and other organizations in order to:

- a) Plan and provide your care and treatment.
- b) Communicate with health care professionals who care for you.
- c) Describe the care you receive.
- d) Obtain reimbursement from other private insurers or government programs.
- e) Verify that services billed were actually provided.
- f) Educate health professionals.
- g) Inform public health officials charged with improving health care.
- h) Assess and improve the services provided and the outcomes achieved.

- i) Pay for services you receive.
- j) Inform you about other public programs and services.

PerformCare and its partners and providers will not use or disclose your protected health information except as described in this notice, or as otherwise authorized by law.

#### V. For more information or to report a problem:

If you have questions and would like additional information, you may contact our Member Services department at **1-877-652-7624**.

If you believe your privacy rights have been violated, you may file a complaint with the PerformCare privacy officer at **1-609-689-5400** or with the secretary of the U.S. Department of Health and Human Services. There will be no retaliation for filing a complaint.

#### VI. Examples of disclosures for treatment, payment, and health operations

- We will use your health information for treatment and care management.
  Information obtained by a care manager, physician, or other member of your health care team will be added to your record and used to determine the course of treatment and referral that should work best for you.
- We will use your health information for payment.
  PerformCare is responsible for making payments to providers who have been authorized to serve your behavioral health needs. As a result, we will disclose information as required to ensure an accurate billing for services.
- We will use your health information for regular health operations.
  Members of a quality assurance team may use information in your health record to assess the care and outcomes in your case and others like it. This information will then be used in an effort to continually improve the quality and effectiveness of the health care and service we provide.

#### VII. Others who may receive your health information

We may use or disclose your protected health information in the following situations without your authorization or providing you the opportunity to agree or object. These situations include:

**Required By Law**: We may use or disclose your protected health information to the extent that the use or disclosure is required by law. The use or disclosure will be made in compliance with the law, and will be limited to the relevant requirements of the law. You will be notified, if required by law, of any such uses or disclosures.

**Public Health**: We may disclose your protected health information for public health activities and purposes to a public health authority that is permitted by law to collect or receive the information. For example, a disclosure may be made for the purpose of preventing or controlling disease, injury or disability.

**Legal Proceedings**: We may disclose protected health information in the course of any judicial or administrative proceeding, in response to an order of a court or administrative tribunal (to the extent such disclosure is expressly authorized), or in certain conditions in response to a subpoena, discovery request or other lawful process.

**Law Enforcement**: We may disclose protected health information for law enforcement purposes.

**Research**: We may disclose your protected health information to researchers when their research has been approved by an institutional review board that has reviewed the research proposal and established protocols to ensure the privacy of your protected health information.

**Criminal Activity**: Consistent with applicable federal and state laws, we may disclose your protected health information, if we believe that the use or disclosure is necessary to prevent or lessen a serious and imminent threat to the health or safety of a person or the public.

## **SECTION V**

## **Special Circumstances**



- Legal guardianship
- Step parents
- Families in the uniformed services (military)
- Families involved in child welfare (DCP&P)
- Homeless young adults

In this section you will find information about special circumstances faced by some of our families.

#### Legal guardianship

Wherever this guide makes reference to a parent, this includes natural or adoptive parents, or legal guardians.

#### How do I become a legal guardian for my young adult (18 and older)?

Legal guardianship and the decision about what types of guardianship you may need for a young adult are handled through private legal arrangement. Contact your local family court for information on the process for obtaining guardianship of an adult.

#### Step parents

#### I am the child's step-parent. Why can't I register my step-child?

We recognize the central role step-parents play in the lives of many children. However, as a step-parent, your legal relationship extends to your spouse, but not your spouse's children. We must have the consent of a parent or legal guardian before you can access services for a step-child, unless you document that you have adopted or have legal guardianship of the child.

Consent must be obtained each time you call. Alternately, the parent/legal guardian may send us a signed Release of Information indicating you may call to access services for the child.

#### Military families

## I am stationed at a military installation in New Jersey. Can I access services for my child?

In most cases, yes. As long as your child/family meets other eligibility criteria, including currently living in New Jersey.

The network of service providers available to families in the Children's System of Care is almost exclusively limited to providers doing business in New Jersey, so orders alone are insufficient to authorize services for your child.

One exception to this is for eligibility for developmental disability services. You must apply for these services in the state that is your Home of Record, regardless of current physical address.

#### DCP&P involved families

## Why am I asked if I am involved with DCP&P (child welfare) when I call PerformCare?

PerformCare will ask you whether you have DCP&P (Division of Child Protection & Permanency) involvement because we have specially trained staff on site who are sensitive to the needs of families involved with child welfare services.

Accessing behavioral health, substance use, or developmental disability services for your child or children facing challenges is a responsible, strong decision as a parent.

### Homeless young adults (Adolescent Housing Hub)

#### I am homeless and need a safe place to stay. Can you help?

A young person between the ages of 18 and 21 experiencing homelessness may contact PerformCare to find out about housing and supports available to help. When a youth calls, he or she will be asked a series of questions, including current living situation and needs for housing. Based on the details given, the youth's name will be posted on the secure Adolescent Housing Hub, and the name and contact information for 3 housing programs that have immediate openings will be given to the youth to contact. Housing programs may also outreach to the youth directly.

## **Notes**


1-877-652-7624

www.performcarenj.org