



Youth and Family Guide

NJ Children's System of Care

Administered by PerformCare®

www.performcarenj.org

6005PC-16504

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Dear Parent/Legal Guardian:

Thank you for contacting PerformCare. We want to take this opportunity to welcome your family to the New Jersey Children's System of Care (CSOC). The CSOC serves youth with emotional and behavioral health care needs, youth with intellectual and developmental disabilities, youth with substance use challenges, and their families. CSOC is committed to providing services based on the needs of the youth and family in a family-centered, community-based environment. PerformCare works with CSOC to help you get the care your child needs, and we are committed to providing you exceptional customer service.

Enclosed you will find a copy of the Youth and Family Guide. Please refer to the Guide for information about how the Children's System of Care works, along with information about your rights, privacy, and useful community resources. The Youth and Family Guide is also available on our website, www.performcareNJ.org, along with the latest information on the CSOC.

You will receive more information from PerformCare soon, depending on what services your child will be accessing. PerformCare is happy to discuss service options with you at any time. You can call PerformCare 24 hours a day, seven days a week, 365 days a year, at **1-877-652-7624**. We look forward to serving you.

Sincerely,

PerformCare

NJ Children's System of Care

Administered by PerformCare®

Youth and Family Guide

Discrimination is against the law

PerformCare complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. PerformCare does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

PerformCare reduces language barriers to accessing services through the New Jersey Children's System of Care by:

- Providing free aids and services to people with disabilities to communicate effectively with us, such as:
 - Written information in other formats (large print, audio, accessible electronic formats, and other formats).
 - Telecommunication devices such as Device for the Deaf (TDD) and Text Telephone (TTY) systems to enable individuals who are deaf, hard of hearing, or speech-impaired to use the phone to communicate.
- Providing language services at no cost to people whose primary language is not English, such as:
 - Qualified interpreter services.
 - Information written in other languages.

If you need these services, contact PerformCare at 1-877-652-7624 or [TTY (for the hearing impaired) 1-866-896-6975]. We are available 24 hours a day, 7 days a week.

If you believe that PerformCare has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can submit a complaint by mail or phone, by either calling PerformCare's Quality department at 1-877-652-7624 or by writing to: PerformCare

Attn: Quality Department
300 Horizon Center Drive, Suite 306, Robbinsville, NJ 08691

If you need help filing a complaint, PerformCare's Quality department is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at

<https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue, SW, Room 509F, HHH Building
Washington, DC 20201

1-800-368-1019, 1-800-537-7697 (TDD)

Complaint forms are available at

<http://www.hhs.gov/ocr/office/file/index.html>.

Multi-language interpreter services

Attention: If you do not speak English, language assistance services are available to you at no cost. Call 1-877-652-7624 (TTY: 1-866-896-6975).

Spanish: Atención: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-877-652-7624 (TTY: 1-866-896-6975).

Portuguese: Atenção: Se fala português, encontra-se disponível serviço gratuito de intérprete pelo telefone 1-877-652-7624 (TTY: 1-866-896-6975).

Arabic:

ملحوظة: إذا كنت تتحدث اللغة العربية، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم (رقم هاتف الصم والبكم: 1-877-652-7624 (TTY: 1-866-896-6975).

Haitian Creole: Atansyon: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele 1-877-652-7624 (TTY: 1-866-896-6975).

Chinese Mandarin: 注意: 如果您说中文普通话/国语, 我们可为您提供免费语言援助服务。请致电: 1-877-652-7624 (TTY: 1-866-896-6975)。

Korean: 주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-877-652-7624 (TTY: 1-866-896-6975) 번으로 전화해 주십시오.

Bengali: লক্ষ্য করুন: যদি আপনি বাংলা, কথা বলতে পারেন, তাহলে নিঃখরচায় ভাষা সহায়তা পরিষেবা উপলব্ধ আছে। ফোন করুন ১-৮৭৭-৬৫২-৭৬২৪ (TTY: 1-866-896-6975)।

French: Attention : si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-877-652-7624 (TTY: 1-866-896-6975).

Vietnamese: Chú ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-877-652-7624 (TTY: 1-866-896-6975).

Hindi: ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। 1-877-652-7624 (TTY: 1-866-896-6975) पर कॉल करें।

Chinese Cantonese: 注意: 如果您使用粵語, 您可以免費獲得語言援助服務。請致電 1-877-652-7624 (TTY: 1-866-896-6975)。

Polish: Uwaga: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 1-877-652-7624 (TTY: 1-866-896-6975).

Urdu:

توجہ فرمائیں: اگر آپ اردو بولتے ہیں، تو آپ کو زبان کی مدد کی خدمات مفت میں دستیاب ہیں۔ کال کریں 1-877-652-7624 (TTY: 1-866-896-6975)۔

Turkish: Dikkat: Türkçe konuşuyorsanız dil yardımı hizmetlerinden ücretsiz olarak yararlanabilirsiniz. 1-877-652-7624 (TTY: 1-866-896-6975) numaralı telefonun arayın.

Russian: Внимание: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-877-652-7624 (TTY: 1-866-896-6975).

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Helpful Numbers

PerformCare: **1-877-652-7624** — 24 hours a day, 7 days a week, 365 days a year

Website: **www.performcarenj.org**

My Child's CYBER ID: _____
(See Getting Started in the Children's System of Care in Section I for more information.)

Care Manager: _____

In-Home Provider: _____

Primary Care Provider: _____

Dentist: _____

Other Important Numbers: _____



Section I: Welcome to the New Jersey Children’s System of Care

- About us.
- Our mission.
- How we can help you.
- How you can help us.
- Getting started in the Children’s System of Care.

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

About us

PerformCare has been connecting New Jersey's families and young people with the care they need in the most appropriate setting since 2009. PerformCare helps families access publicly funded services for youth with behavioral, emotional, intellectual, developmental, and/or substance use challenges.

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

Our mission

We help people get care, stay well, and build healthy communities. This includes helping families and caregivers create a more stable and healing environment for children, address barriers to well-being, and maximize youth and family strengths.

How we can help you

Beginning with just a phone call, PerformCare can help you connect your child to the behavioral health, substance use, or developmental disability services he or she needs to be well and thrive. 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 developmental disability.
- Your child is refusing to attend school or has repeated lateness or absences, or if you have other concerns about his or her school performance.
- Your child shows physical and/or 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, such as death, divorce, or relocation, and does not 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 would like to know more about the types of services available.

Early response and prevention

The New Jersey Children's System of Care (CSOC) has achieved tremendous results. By engaging youth in support services at an earlier age, CSOC can often prevent a more serious and difficult behavioral problem from developing.

Earlier interventions mean children have a better chance of positive outcomes and being happy and healthy.

How you can help us

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

- Let us know if you have moved or your contact information has changed.
- Keep your benefit information updated with your primary health insurance plan. The services available through CSOC are 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:
 - Making appointments with the providers we connect you with.
 - Cancelling appointments when you cannot make them.
 - 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 want more information, call us toll free at **1-877-652-7624**, 24 hours a day, 7 days a week, 365 days a year. Our Member Services department will help connect you to the right person or resource you need.

Getting information

By phone

The best way to contact PerformCare is by phone at **1-877-652-7624**. 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. 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 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 about the Children's System of Care, 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 available services.
- Fact sheets and frequently asked questions (FAQs).
- Links to local community resources.
- Application materials.

Our website is www.performcarenj.org. Most of the information you will need can be found in the **Families** section of the site. 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 at **1-877-652-7624**.

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.

For those who 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.

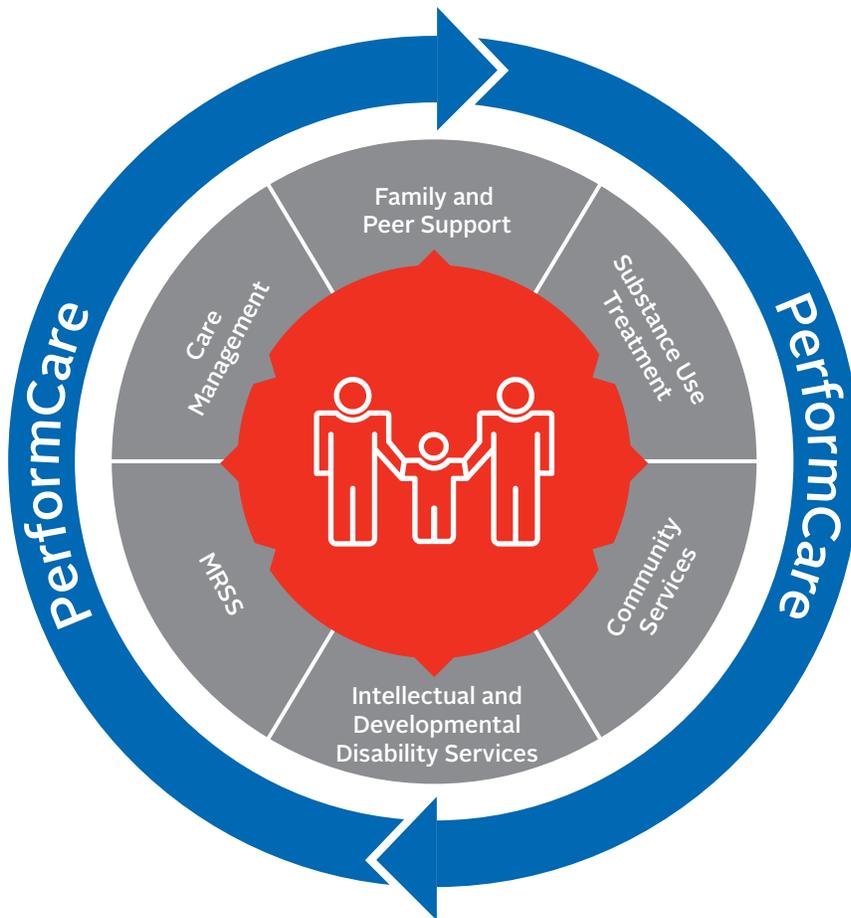
For those who are deaf or hard of hearing, our TTY number is **1-866-896-6975**.

Getting started in the Children's System of Care

When you first call PerformCare to access services, we register your child and then generate a unique identification 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.

System of Care for the State of New Jersey



Care Management

Including care management organizations

Family and Peer Support

Family-support organizations, advocacy, and other supports for families

Substance Use Treatment

For eligible youth up to age 18

Intellectual and Developmental Disability Services

MRSS

Mobile response and stabilization services for urgent needs

Community Services

School, child protection, and other local resources

The System of Care approach

Parents and 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 and 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 help your child and family.

When you call PerformCare to access a service or support, your child becomes part of the **New Jersey Children’s System of Care** — the division of state government that funds the services. The actual *system of care* is a special approach to how, when, and where services and supports are offered.

The system of care method 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 challenges. At that time, there were almost no community-based treatment options for families, and private insurance resources were limited. 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 within child protective services. In 2013, it began serving children with developmental and intellectual disabilities and their families. The Children's System of Care also provides eligible youth coordinated access to substance use treatment services.

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.
- Ensures 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 Children's System of Care is committed to providing emotional or behavioral health, intellectual or 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 (Medicaid) or other health benefits programs.
- 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.
- Provided in the least restrictive, most natural setting appropriate to meet the needs of the youth and his or her family.
- Family-driven, with families engaged as active participants at all levels of planning, organization, and service delivery.
- 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.
- Culturally competent, with agencies, programs, services, and supports that are responsive to the cultural, racial, linguistic, and ethnic differences of the populations they serve.
- Protective of the rights of youth and their families.

Child-centered care in the right place

No matter the challenge, PerformCare can direct a child's family to a CSOC program that will put him or her on the path to a better quality of life. CSOC ensures that children and young adults receive care in the setting best suited to their needs.



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 access Children’s System of Care services?

You can access services for youth who reside in New Jersey and meet specific eligibility criteria (including age limits) for each service type:

- Youth (up to their 21st birthday) with **emotional or behavioral challenges** must be in need of services that are not typically provided through primary health insurance. Typical services include outpatient individual therapy or partial care services. Services must meet the specific eligibility rules for each service type.
- Youth with **intellectual or developmental disabilities** must first be determined “Developmental Disability (DD) eligible” to receive services. The Application for Determination of Eligibility for Children Under Age 18 with Developmental Disabilities is available on our website, **www.performcarenj.org**. If you do not have access to the internet, PerformCare can mail you an application.
 - Youth who were determined DD eligible by the New Jersey Division of Developmental Disabilities do not have to reapply to receive services in the Children’s System of Care. Youth ages 18 – 21 years must complete an application through the New Jersey Division of Developmental Disabilities.
- Eligible 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.
- Housing services through the **Adolescent Housing Hub** (AHH) are available to eligible homeless youth, and youth at risk for homelessness, ages 16 – 21 years.

Do I pay for services?

There is no charge for calling PerformCare. Most of services offered through CSOC do not have an additional cost, but please review the specific services requested to confirm the out-of-pocket expense 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. If you have private insurance, please contact your carrier’s complex needs manager for information on benefits and coverage available.

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 to continue receiving services. There are special limited NJ FamilyCare options available to certain children who 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 or another Medicaid plan, 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 behavioral health services available through health insurance. System of Care services are designed for youth whose complex needs 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 does not seem to be showing any improvement.
- 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 additional services and supports that are publicly funded.

What kinds of services are there?

The Children’s 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 to a 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 1 or more of the following categories:

- Mobile Response and Stabilization Services (MRSS) for youth in crisis emergencies.
- BioPsychoSocial Assessment (BPS).
- Care Management Services.
- Intensive In-Home or Intensive In-Community Services (IIH/IIC).
- Substance use treatment services.
- Out-of-home treatment (OOH).
- Support for families and caregivers through a Family Support Organization (FSO).
- 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 associate. 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 (such as a knife or gun).
- Current active violence involving 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 not need to call PerformCare to access them:

- **Psychiatric Emergency Screening Services** 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.
- **Children's Crisis Intervention Services (CCIS)** is 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 themselves or others.

Your child may also be referred to **Partial Hospitalization** for up to 6 hours a day, and up to 6 days a week, for behavioral health stabilization and treatment.

Mobile Response and Stabilization Services: urgent care for youth in crisis

In a true emergency, time is of the essence and police or a hospital may be required. However, in urgent behavioral situations — where a person's immediate safety is not at risk but a child's behavior is escalating beyond a parent or caregiver's ability to manage it — we are able to connect families to their local Mobile Response and Stabilization Services (MRSS) provider. Mobile Response is available for all children in crisis. This includes if the crisis is related to the child's behavioral or emotional needs, intellectual or developmental disabilities, or both.

Mobile Response will respond to the crisis, in person, within 1 hour of your call to us. Typically, the crisis is in the home, but if it 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.

BioPsychoSocial Assessment

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

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

If you are told that your child requires a BPS 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 child's and family's needs.
- Within **1 week after you set the appointment**, the clinician will meet with you to complete the assessment and recommend supports that 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 and supports 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.
- If you disagree with a decision, and would like to file a Reconsideration or appeal, please refer to **Section III** of this guide.

In some cases, your child might need an assessment completed by someone with specialized training 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 BPS Assessment authorized by PerformCare. However, we cannot authorize a BPS Assessment at the request of another entity such as a school. In addition, only 2 BPS 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 care manager's primary job is to help coordinate all the different services and resources needed, a child may only have 1 type of care 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 (CFT) meetings, and implement Individual Service Plans (ISPs) for each youth and his or her family. The CMO uses a wraparound approach to planning for each youth and provides a single point of accountability for the services and the supports needed to maintain stability. Care Management also provides access to your local Family Support Organization.

Care Management through Mobile Response and Stabilization Services (MRSS): Youth who receive ongoing MRSS 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 (MST) and Family Functional Therapy (FFT): These 6-month, intensive family therapy models are often offered to youth involved with, or at risk of, involvement with the juvenile justice system.

Other Care Management services: Some of the other services offered in the Children's System of Care have care management integrated into the service delivery model. That means for a youth receiving 1 of these services, it would not be appropriate to receive additional care management through a CMO.

Intensive In-Community (IIC) and Intensive In-Home (IIH)

While traditional therapies are typically provided at the health care provider's office location, Intensive In-Community (IIC) and Intensive In-Home (IIH) 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 cover a variety of services geared to assist youth with challenging behaviors that may impact their ability to remain at home.

Some examples of these services include:

Intensive In-Community services (IIC) — These therapeutic services are intended for a restoration of a youth's functional level after a decline related to behavioral health episode or a significant life stressor or trauma. These services are provided by licensed practitioners, and may include individual and/or family therapy interventions.

Behavioral Assistance (BA) — BA is a process of intervention and ongoing evaluation resulting in effective modification of a youth’s identified behavior(s). The services involve applying positive behavioral principles within the community, using culturally based norms to foster behaviors that are rehabilitative and restorative. (IIC)

Social Emotional Learning (SEL) services — SEL services help youth develop functional social and emotional skills that are critical to achieve optimal outcomes in their behavioral health treatment. SEL is designed to build strengths in self-management, self-awareness, decision-making, social awareness, and interpersonal interactions. (IIC/BA)

Clinical and therapeutic interventions — These services provide individual and family treatment approaches to improve the behavioral and emotional functioning in youth with challenges related to an intellectual or developmental disability. (IIH)

Applied Behavioral Analysis (ABA) — ABA is a set of habilitative services, designed for decreasing dangerous behaviors while assisting youth in acquiring and retaining self-help, communication, and adaptive skills. A focus is put on a transfer of skills to the youth while working with/training the youth’s parent or caregiver to implement the behavioral plan. (IIH)

Individual Support Services (ISS) — ISS is skill development for activities of daily living, including self-care tasks and the enabling of an individual to live independently in the community. (IIH)

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 FamilyCare). Your health insurance carrier can explain the benefits available.

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

PerformCare is able to refer and authorize substance use treatment services for eligible youth ages 13 up until 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 uses 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 clinicians who may also have specialized training and certification in substance use such as licensed clinical alcohol and drug counselors (LCADCs).

Out-of-home treatment (OOH)

While the goal of the Children's System of Care is to provide the services and supports necessary to keep a child at home and connected to his or her school and community, sometimes this is not possible for the safety of the child or the community, or the unique challenges of the child or family. Recognizing that your child may need 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 (OOH) treatment, PerformCare will work with your CMO to identify the least restrictive type of treatment setting to best meet your child's identified needs. Your CMO, through the Child Family Team process, will help you identify the specific treatment program to serve your child.

OOH treatment settings are available throughout 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 and larger specialized behavioral health settings.

Depending on your child's needs, you may be referred to multiple potential OOH providers. You are encouraged to use initial meetings or interviews to ask questions, gather information, and select the provider you feel will best meet your child's needs.

When a child is admitted into OOH treatment, you, your care manager, and the Child and Family Team will monitor the progress of your child together, 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 OOH treatment is an important part of successful transition home.

OOH treatment settings include, but are not limited to:

Treatment Homes (TH) — This setting is for youth who are unable to achieve stability due to persistent behavioral and/or mental health difficulties, however are capable of being maintained in a clinically supported homelike setting with needed clinical support and attend a local community school. This service is also for youth who are transitioning from a more intense OOH treatment setting and who are not yet clinically ready to return to a nonclinical setting.

Group Homes (GH) — A community-based home designed for youth with significant behavioral and emotional disturbances but with some capability to engage in community-based activities. Group homes offer a less intensive treatment environment than a residential treatment center. Youth eligible for Intellectual/Developmental Disability (I/DD) group homes have moderate needs involving supervision and carrying out activities of daily living (ADLs). They usually exhibit some ability to carry out ADLs and their medical needs are generally stable, but require periodic, nonclinical specialized oversight.

Residential Treatment Center (RTC) — An RTC provides 24-hour staff-supervised all-inclusive clinical services in a community-based therapeutic setting for youth who present severe and persistent challenges in social, emotional, behavioral, and/or psychiatric functioning. Youth receive individualized clinical interventions, psychopharmacology services (when applicable), education, medical services, and structured programming within a safe, structured environment with a high degree of supervision. Treatment provides rehabilitative services including, but not limited to, social, psychosocial, clinical, medical, and educational services. Certain RTCs also include therapies for youth with co-occurring substance use related disorders.

Specialty Residential Services (SPEC) — SPEC provides highly supervised, 24-hour care within a community-based out-of-home treatment setting for youth who manifest significant emotional and/or behavioral challenges that require a more specialized clinical intervention. Specific behavioral challenges associated with serious behavioral health issues that may benefit from specialty treatment services include extreme assault or aggression, fire setting, problematic sexual behavior, and animal cruelty.

Psychiatric Community Home (PCH) — PCH provides highly supervised, licensed, 24-hour care within an intensive treatment program for youth with serious psychiatric conditions. Treatment in a PCH should include family involvement, where clinically appropriate. A PCH is appropriate for a youth who has received inpatient services and/or who cannot be maintained in his or her current living arrangement with a reasonable degree of safety.

Support for families and caregivers

Family Support Organizations

Family Support Organizations (FSOs) are nonprofit, county-based organizations that work collaboratively with PerformCare, Care Management, state agencies, and other providers to offer face-to-face family support to families and ensure that the System of Care is responsive to the needs of children and families.

FSOs use peer-based Family Support Partners (FSPs) — parents and caregivers who have raised a child with special needs, whether the needs are emotional or behavioral challenges, or intellectual or developmental disabilities. FSPs will work closely with families to provide support from their own shared experiences, offer guidance on ways to maximize available resources, connections to other community supports, and advocacy to make sure your child's and family's needs are heard.

Families of youth referred to Care Management Organizations can also choose to have an FSP from the local FSO as part of their Child and Family Team.

Family Support Services

Family Support Services (FSS) are available for youth who are **determined eligible for developmental disability services and meet the criteria for FSS**. The FSS described below may be provided based on availability and appropriateness to the needs of your child and family. An FSS application must be completed to access these supports.

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 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 cannot be used to restrain the youth.

Educational Advocacy is a service provided to youth and their families when the youth needs in-depth help with education-related needs.

Respite means “break” or “relief.” Respite services are 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.

Respite 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. There are several different settings for respite, including after-school respite, overnight stays, and weekend recreation. Please note that respite services are dependent upon funding availability.

Financial Support toward Summer Camp

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.

One-to-One Aide services may also be available for youth deemed eligible for CSOC developmental disability services who would otherwise be unable to participate in camp.

Summer camp supports are based on available resources in a given fiscal year. Families and 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 both of these are true:

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

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 or 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.

Family Leaders for PerformCare

Family Leaders for PerformCare is a small group of parents and caregivers who partner with PerformCare's Executive Director to ensure that children and families are informed of System of Care services and benefits and how to access care. Family Leaders have an essential role in ensuring our communications are responsive to the needs of the families and youth we serve.

The mission of Family Leaders is for families to partner with PerformCare to ensure that the strengths and needs of the children, youth, and families are upheld as driving elements of the Children's System of Care.

Through a relationship in which families and PerformCare work together to continually learn and teach one another, we combine and strengthen our voices to ensure that PerformCare fulfills its commitment to provide access to "the right care at the right time."

If you are the parent of a child involved with services through PerformCare, and would like to become one of our Family Leaders, contact us at **1-877-652-7624**. We welcome your ideas and input.

Youth involvement and peer supports

The role of a youth's voice in making sure they get the right care and treatment, as well as in giving feedback on the effectiveness of services and policies, is very 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 as much as possible in setting goals and creating their own plans.

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. The following examples are some of the core opportunities for youth to get involved.

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.

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

For more information, contact your local Family Support Organization (FSO). The FSO contact information is available on our website.

Youth Leadership Program

Young advocates with developmental disabilities are encouraged to become powerful advocates for personal and systems change. The New Jersey 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 regarding the Youth Advisory Boards is available online at socialwork.rutgers.edu/InstituteForFamilies/officeofchildwelfareinitiatives/TFY/Projects/statewideYAB.aspx.

2NDFLOOR — 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 www.2NDFLOOR.org. 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 **Additional Resources** section of this guide, or on the PerformCare website (www.performcarenj.org). Resources include 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 service providers have internal Youth Advisory Boards or other formal or informal ways of involving youth in service design and delivery.

Services not provided through the System of Care

Outpatient services

Outpatient services are individual or group behavioral health treatment services provided at a provider's 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 phone 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.

Partial Care Services

Your child may be referred to a Partial Care program through a Care Management Organization. Partial care is an intensive, therapeutic day treatment program that may or may not be hospital-based, intended for youth with complex behavioral health needs. The program provides a stable environment for clinical treatment services and activities for daily living, recreation, and socialization (based on individual need), for up to 5 days a week.

School and education services

The Children's System of Care does not provide school or educational services that would otherwise be covered under the Individual with Disabilities in Education Act (IDEA), or similar public education law, such as occupational or 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 a 504 plan.

Free assistance regarding school services is also available to families from the Statewide Parent Advocacy Network (SPAN) Parent Training and Information Center. For more information, visit www.spanadvocacy.org.

Experimental or investigational treatments

Services provided through the New Jersey 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 or reimbursement, or use providers of services that are considered experimental or investigational, including medication and treatments not approved by federal and/or state regulators.

Transition to adult supports

The New Jersey 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.

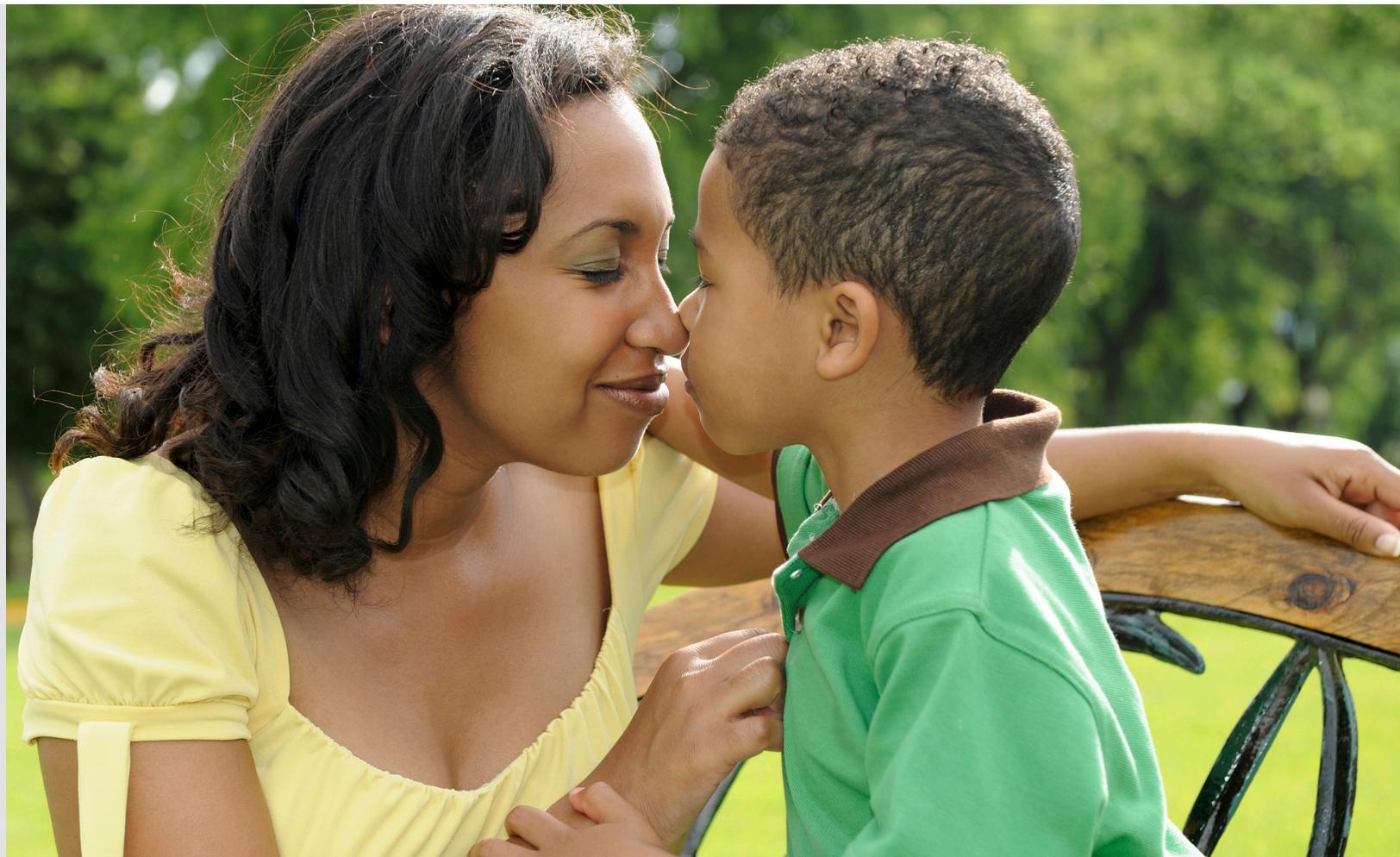
Your service providers should provide treatment or supports with an honest discussion and constant attention to preparing for transition or discharge, whether this is changing to a different type of service or “aging out” into adult services.

If you receive 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 or community connections that will help your child and family succeed. Your FSO may also be of assistance with transition.

For more information about transitioning to adult services for behavioral health and substance use, please contact the **New Jersey Division of Mental Health and Addiction Services (DMHAS)**. DMHAS is the state mental health authority (SMHA) and the Single State Authority on Substance Abuse (SSA) that plans, monitors, evaluates, and regulates New Jersey’s mental health and substance abuse prevention, early intervention, treatment, and recovery efforts. You can visit the DMHAS website at www.state.nj.us/humanservices/dmhas/home.

You can directly access the DMHAS’ Directory of Mental Health Services by visiting www.state.nj.us/humanservices/dmhas/home/hotlines/MH_Dir_COMPLETE.pdf.

New Jersey’s Division of Developmental Disabilities (DDD) provides public funding for services and supports that help New Jersey adults ages 21 and older with intellectual and developmental disabilities live as independently as possible. Services and supports are available in the community from independent providers, and in 5 state-run developmental centers. Additional information on DDD can be found at www.nj.gov/humanservices/ddd/home.



Section III: Youth and Family Rights, Quality and Reporting Concerns

- Youth and family rights.
- Notifying you of changes to your care.
- Our commitment to quality.
- Concerns, complaints, and 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 child is entitled to certain rights when you sign him or her up for care. As a parent or legal guardian, you also have certain rights.

It is the policy of PerformCare and the 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' processes for conducting business.
- Request and receive information regarding their family's 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 or 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 or 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.
- For families with NJ FamilyCare, the ability to request a Medicaid Fair Hearing.

What are notification rights?

You have the right to know when your child'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 or legal guardian of the child (and/or your child, if applicable) give notice that you do not want the service.
- Your child is admitted somewhere that makes him or her ineligible for other services.
- Your child 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. Generally, there are three options for a family:

- **Complaint:** A concern regarding the quality of services, filed with PerformCare via a phone call or in writing.
- **Reconsideration:** A request to PerformCare to change a decision regarding an authorized service, through a phone call or in writing.
- **Appeal:** Used when a request for service(s) has been denied, terminated, or reduced. A formal filing is required in writing only to the New Jersey Children's System of Care.

Complaints and concerns

PerformCare is responsible for resolving complaints for the New Jersey 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 child's care will not be impacted 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 to PerformCare.

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 PerformCare has authorized or about the treatment you have received while on the phone with us, you may request to file a complaint at any time during a call.

If you suspect your provider is engaging in fraudulent activity around payments or service delivery, you should call PerformCare right away. Examples of fraud and abuse include:

- 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.

You can submit a complaint by calling PerformCare at **1-877-652-7624** or in writing to:

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

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

Reconsiderations

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 on the services for which the youth or family is eligible.

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 to help you resolve issues more quickly than the Medicaid fair hearing process, the NJ FamilyCare grievance review process, or the 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.

You can request Reconsideration by calling PerformCare at **1-877-652-7624**, or in writing by mailing your request to:

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

Continuing services during the Reconsideration process

While a Reconsideration is under review, your child can continue to receive the services currently authorized until you are notified of our decision.

- For example, a family was **originally** authorized for **10 hours** of respite services a week. The family was then later **reauthorized** for **5 hours** of respite services a week.

If the family disagrees with the decrease in hours, they can file a Reconsideration. The family will continue to receive **5 hours** of service throughout the Reconsideration process until a decision is made.

PerformCare will attempt to reach a decision within 5 business days of the request if no other information is submitted, and will notify you within 48 hours of making the decision. In the event a resolution cannot be achieved within that time, the Reconsideration decision shall be made within 30 days of the request. Reconsiderations of services are reviewed by the Director of Clinical Services and/or Medical Director.

Please note that not all services are eligible for a Reconsideration. You may call PerformCare at **1-877-652-7624** to answer any questions and assist you in the process.

Appeals

Formal appeals are available to families and youth when a request for service(s) has been denied, terminated, or reduced. Families can also file for an appeal if there is a disagreement with the type of service authorized.

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

A request for an appeal must be in writing and made within 20 days of receiving written notice of the decision you disagree with — either an initial service authorization or the result of the Reconsideration or complaint.

Your request must include all of the following:

- 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.
- 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, you should also include that in the request.

The request should be mailed to:

Division of Children's System of Care
Attention: Appeals Unit
P.O. Box 717
Trenton, NJ 08625-0717

The type of review your appeal will receive depends on the particular service at issue and/or your child's insurance coverage.

Fair Hearings and Administrative Hearings

- Appeals involving a child's eligibility to receive developmental disability services are subject to an administrative hearing.
- Appeals involving services funded by Medicaid, New Jersey FamilyCare – Plan A, or programs under the New Jersey Comprehensive Waiver administered by the CSOC are subject to a Fair Hearing.
- Appeals involving services funded by NJ FamilyCare – Plans B, C, or D are subject to the grievance procedure established by the Division of Medical Assistance and Health Services or an administrative hearing.
- Appeals involving out-of-home services and intensive in-home services not funded by Medicaid or New Jersey Family Care are subject to an administrative hearing.

Fair Hearings and Administrative Hearings are court-like proceedings heard by an Administrative Law Judge (ALJ) within the Office of Administrative Law. Families have the right to have a representative, although representation is not required.

Dispositional reviews

- Appeals involving non-clinical services, including respite, assistive technology devices, and other family support services are subject to a dispositional review.
- Appeals involving contribution to care assessments are subject to a dispositional review.

A dispositional review is an informal, independent examination conducted by a review officer within the Department of Children and Families.

Please be advised the timeframe for each type of appeal varies. However, appeals generally take at least several months to be resolved. Families are provided specific information regarding the timeframe during the appeal process.



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 when they move from 1 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. Some health information has greater protections afforded based on its level of sensitivity, such as behavioral health information and an individual's HIV/AIDS status.

Why all this concern about privacy?

In the age of electronic databases, privacy is an increasing concern for many people. The protections pursuant to HIPAA 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.

As families' health information is protected under state and federal laws, families should know that their health information is securely and properly held by those who provide, authorize, 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 the health information that PerformCare, CSOC, and providers use for making decisions about them.
- Requesting an amendment of the health information listed.
- 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. Families may either review this notice on the PerformCare website or request a mailed copy by phone.

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, care, or medical management records.
- Any other records used for making health care payment decisions about the individual.

Records held by PerformCare and other business associates of the New Jersey Department of Children and Families/Children's System of Care (DCF/CSOC) entities are considered part of the Designated Record Set. Individuals have 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 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 on such a request, everyone who might need to know about it will be notified. This may include insurance companies and providers who treat the youth.

Either the youth (if age 14 or older) or the parent or 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 its 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.

New Jersey State law will prohibit the transmission on some sensitive health information with the member's informed consent (as cited below in **Confidentiality laws and regulations**).

Non-routine disclosure of information

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

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

Examples of non-routine disclosures 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 and 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

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

PerformCare considers the privacy of your information 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.

Authorizing the release of health information

Except when information is used for routine purposes, a **Release of Information Authorization** must be obtained from the parent or 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 phone.

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

Consent to release information for youth ages 14 and older

Where a youth 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 or legal guardian or third party. If more than 1 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 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 publicly funded services for children and youth with behavioral health, developmental or intellectual 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 (PHI) is any information, whether oral or recorded in any form or medium, 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.
- Identifies the individual or with respect to which there is a reasonable basis to believe the information can be used to identify the individual or a member of the individual's household 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 PHI and disclose it to providers and other organizations to:

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

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

IV. 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**, the State of New Jersey Department of Banking & Insurance at **1-888-393-1062**, or with the secretary of the U.S. Department of Health and Human Services. There will be no retaliation for filing a complaint.

V. 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 to continually improve the quality and effectiveness of the health care and service we provide.

VI. Others who may receive your health information

We may use or disclose your PHI 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 PHI 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.

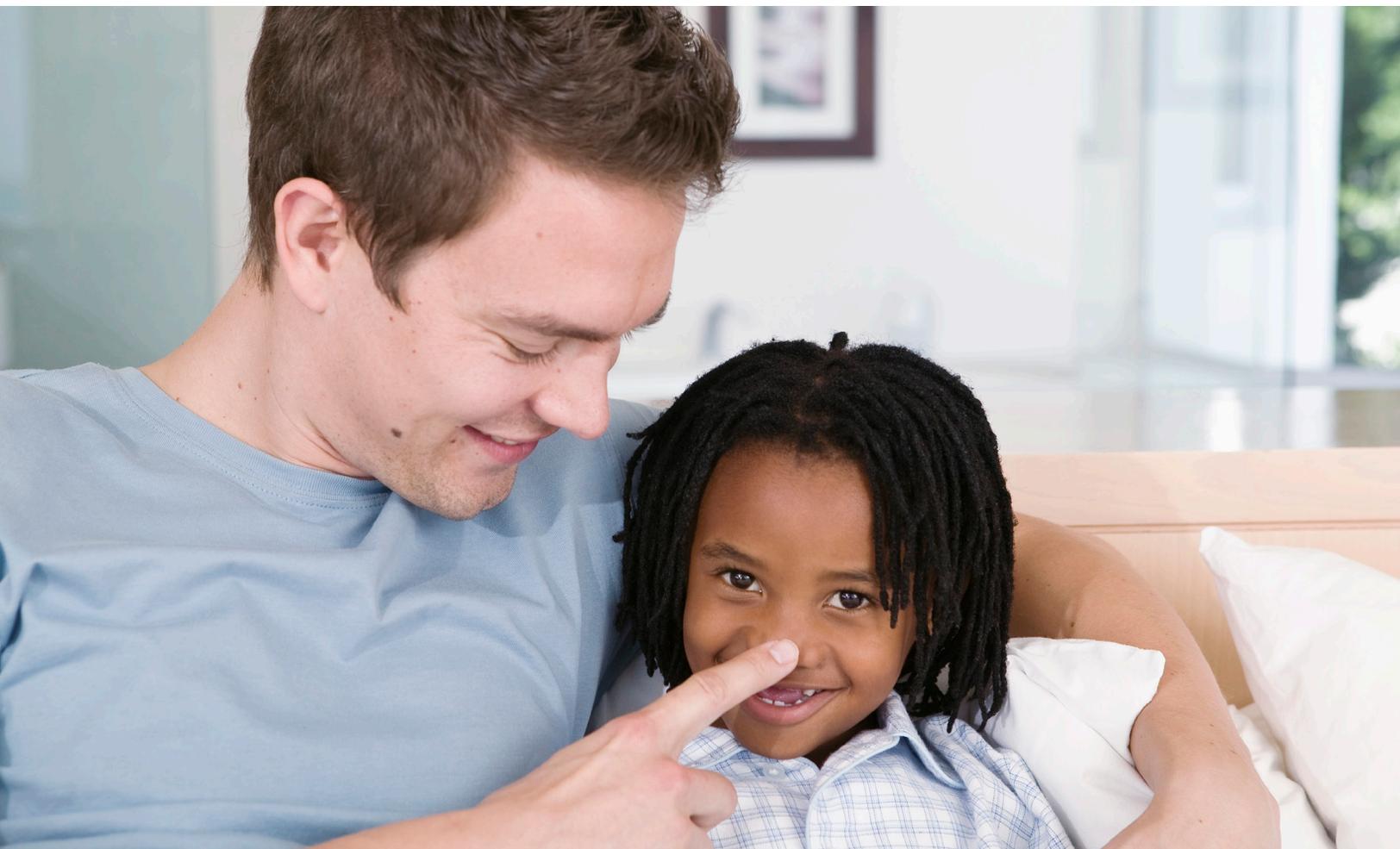
Public health: We may disclose your PHI for public health activities and purposes to a public health authority that is permitted by law to collect or receive the information. For example, a disclosure may be made for the purpose of preventing or controlling disease, injury or disability.

Legal proceedings: We may disclose PHI 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 PHI for law enforcement purposes.

Research: We may disclose your PHI 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 PHI.

Criminal activity: Consistent with applicable federal and state laws, we may disclose your PHI 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.
- Stepparents.
- 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 refers to a parent, this includes natural or adoptive parents, caregivers, and 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.

Information about potential alternatives to legal guardianship is available online at www.supporteddecisionmaking.com.

Stepparents

I am the child's stepparent. Why can't I register my stepchild?

We recognize the central role stepparents play in the lives of many children. However, stepparents' legal relationship with their spouse does not automatically extend to their spouse's children. We must have the consent of a parent or legal guardian before you can access services for a stepchild, 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 or 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. Your child and family must also meet 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. An 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.

Division of Child Protection and Permanency (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 involvement because we have specially trained staff on-site who are sensitive to and experienced in 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.

Adolescent Housing Hub — for homeless young adults

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

A young person from 16 – 21 years old 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 and the youth's eligibility, 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 contact the youth directly.



Section VI: Additional Resources

- Behavioral health resources.
 - Intellectual and developmental disability resources.
 - Substance use resources (including alcohol use).
-

In this section, you will find information about additional resources available outside of the Children's System of Care that may be useful to your family.

Behavioral health resources

National Suicide Prevention Lifeline

1-800-273-8255 • www.suicidepreventionlifeline.org

The National Suicide Prevention Lifeline provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, 7 days a week. Since its inception, the Lifeline has engaged in a variety of initiatives to improve crisis services and advance suicide prevention.

New Jersey Hopeline

1-855-654-6735 • www.njhopeline.com

The Hopeline is New Jersey's 24/7 peer support and suicide prevention hotline. The specialists at the NJ Hopeline are available to provide confidential phone counseling, support, and referrals to local resources to help youth and families get through difficult times.

Children and Adults with ADHD (CHADD)

1-800-233-4050 • www.chadd.org

CHADD is a national nonprofit, tax-exempt Section 501(c) (3) organization providing education, advocacy, and support for individuals with attention-deficit/hyperactivity disorder.

National Alliance on Mental Illness (NAMI)

1-800-950-6264 • www.nami.org

NAMI is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI is an association of hundreds of local affiliates, state organizations, and volunteers who work in your community to raise awareness and provide support and education that was not previously available to those in need. NAMI's New Jersey affiliate can be reached at **1-732-419-8050** or **www.naminj.org**.

SAMHSA National Helpline

1-800-662-HELP (4357) • www.samhsa.gov

The Substance Abuse and Mental Health Services Administration (SAMHSA) is the agency within the U.S. Department of Health and Human Services that leads public health efforts to advance the behavioral health of the nation. SAMHSA's Treatment Referral Routing Service Helpline provides 24-hour free and confidential treatment referral and information in English and Spanish about mental and/or substance use disorders, prevention, and recovery.

Statewide Parent Advocacy Network

www.spanadvocacy.org

The Statewide Parent Advocacy Network (SPAN) is an independent 501(c) (3) organization that is a "1 stop" for New Jersey families. SPAN is committed to empowering families as advocates and partners in improving education, health, and behavioral health outcomes for children and youth.

Stop Bullying**www.stopbullying.gov**

Managed by the U.S. Department of Health and Human Services, stopbullying.gov provides information from various government agencies on the definitions of bullying and cyberbullying, who is at risk, and how you can prevent and respond to bullying.

Intellectual and developmental disability resources

The New Jersey Division of Developmental Disabilities**www.nj.gov/humanservices/ddd/home**

The Division of Developmental Disabilities provides public funding for services and supports that assist New Jersey adults ages 21 and older with intellectual and developmental disabilities to live as independently as possible. Services and supports are available in the community from independent providers, and in 5 state-run developmental centers.

The New Jersey Division of Disability Services**www.nj.gov/humanservices/dds**

The New Jersey Division of Disability Services publishes an annual resource directory with a wealth of information for individuals with disabilities and their families or caregivers. The directory is available on Division's webpage.

Arc of New Jersey**1-732-246-2525 • www.arcnj.org**

The Arc of New Jersey is a statewide service and advocacy organization for children and adults with intellectual and developmental disabilities, with 20 local chapters serving every county.

Autism New Jersey**1-800-4-AUTISM or 1-609-588-8200 • www.autismnj.org**

Autism New Jersey is the largest statewide network of parents and professionals dedicated to improving the lives of individuals with autism spectrum disorder.

Brain Injury Alliance**1-800-669-4323 • www.bianj.org**

The Brain Injury Alliance of New Jersey is a statewide organization that assists people with brain injuries and their families by providing family support, information, and educational programs.

New Jersey Catastrophic Illness in Children Relief Fund Commission**1-800-335-3863 • www.state.nj.us/humanservices/cicrf/home**

The Catastrophic Illness in Children Fund may be able to help if you have overwhelming medical bills for your child.

The Family Resource Network**1-800-376-2345 • www.familyresourcenetwork.org**

The Family Resource Network is the largest statewide provider of community-based family support services for people with intellectual and developmental disabilities.

Mom2Mom

1-877-914-MOM2 • www.mom2mom.us.com

Mom2Mom is a statewide program that offers peer support for mothers with children of special needs. 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, and help identify and connect you to local resources, and will follow up with you and help you solve challenges.

New Jersey Statewide Independent Living Council

www.njsilc.org

The New Jersey Statewide Independent Living Council (SILC) is a 17-member body appointed by the Governor that maximizes opportunities for people with disabilities through planning and advocacy. The SILC is a separate entity in, but not of, the New Jersey Department of Labor.

Statewide Parent Advocacy Network

www.spanadvocacy.org

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Special Child Health Services

www.state.nj.us/health/fhs/sch/index.shtml

The State of New Jersey’s Department of Health assists families who care for children with complex, long-term medical, and developmental disabilities.

Substance use resources (including alcohol use)

The New Jersey Division of Mental Health and Addiction Services (DMHAS) Treatment Directory

njsams.rutgers.edu/dastxdirectory/txdirmain.htm

DMHAS is the state mental health authority (SMHA) and the single state authority on substance use (SSA) that plans, monitors, evaluates, and regulates New Jersey’s mental health and substance abuse prevention, early intervention, treatment, and recovery efforts.

Narcotics Anonymous

1-800-992-0401 • www.nanj.org

Narcotics Anonymous (NA) meetings are free and open to anyone who thinks he or she might have a substance use problem. Anyone may attend NA, regardless of age, race, sexual identity, creed, religion, or lack of religion. There are also NA meetings designated as “Youth” in their online meeting directory.

Alcoholics Anonymous

Alcoholics Anonymous is a fellowship of men and women who share their experience, strength, and hope with each other that they may solve their common problem and help others to recover from alcoholism.

You can use the websites below to find meetings that are closest to where you are located.

North Jersey, including Hunterdon, Mercer, Middlesex, Monmouth, and Ocean counties

- Intergroup of Northern N.J.
24-hour toll-free: **1-800-245-1377** • www.nnjaa.org.

Trenton, Princeton, and surrounding areas in southern-central New Jersey

- Central Jersey Intergroup
24-hour hotline: **1-609-298-7795** • www.centraljerseyintergroup.org.

South Jersey, including Burlington, Camden, Cumberland, Gloucester, and Salem counties

- South Jersey Intergroup Association
24-hour toll-free: **1-866-920-1212** • www.aasj.org.

Southern Jersey Shore, including Atlantic and Cape May counties

- Cape Atlantic Intergroup
24-hour hotline: **1-609-641-8855** • www.caigrp.org.

NJ Al-Anon/Alateen

1-973-744-8686 • www.nj-al-anon.org

The Al-Anon Family Groups are a fellowship of relatives and friends of alcoholics who share their experience, strength, and hope to solve their common problems. They believe alcoholism is a family illness and that changed attitudes can aid recovery. Al-Anon has 1 purpose: to help families of alcoholics.

NJ Connect

1-855-652-3737 • www.njconnectforrecovery.org

A confidential call line to connect substance users with certified drug and alcohol counselors and connect family members with peer specialists.

NJ Addictions Services Hotline

1-844-276-2777

This 24/7 hotline is staffed by addiction services specialists with Rutgers University Behavioral Health Care (RUBHC) who can provide help to those with substance use needs.

SAMHSA National Helpline

1-800-662-HELP (4357) • www.samhsa.gov

The Substance Abuse and Mental Health Services Administration (SAMHSA) is the agency within the U.S. Department of Health and Human Services that leads public health efforts to advance the behavioral health of the nation. SAMHSA's Treatment Referral Routing Service Helpline provides 24-hour free and confidential treatment referral and information in English and Spanish about mental and/or substance use disorders, prevention, and recovery.

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