



Date: August 23, 2022

Topic: Family and Provider Relations

The New Jersey Department of Human Services' (DHS) Division of Developmental Disabilities (Division) provides funding for supports and services to over 24,500 individuals with intellectual and developmental disabilities (IDD) in community settings.

In an effort to ensure communication and obtain feedback, the Division interacts regularly with various stakeholders (E.g. Individuals, Guardians/Families, Advocacy Groups, etc.) to exchange information. Through this interaction, various subject areas are discussed. One topic communicated to the Division by some families is their experience or fear of retaliation by the service provider of their loved one if they lodge a complaint about care. As described, there is concern about this occurring when allegations of abuse, neglect and/or exploitation are made or when there are disagreements related to care.

DHS and the Division take the topic of retaliation seriously and have zero tolerance for circumstances where a Division funded service provider engages in this practice. The Division defines retaliation as negative action(s) taken by one or more employees of a Division funded entity solely to punish the reporting, or the attempt to report/address, care concerns.

Any individual, guardian or family member is directed to report actual or suspected abuse, neglect and/or exploitation – including an experience of retaliation by a DDD funded service provider by **calling the DDD hotline at 1-800-832-9173 (then press 1) to report it.**

Consumer Protection

There are several layers of oversight, monitoring, incident reporting and investigatory processes in place, some of which are deliberately overseen outside of the Division to avoid any perceived or actual conflicts of interest in the Division directly licensing and/or investigating the providers it funds. The below are areas overseen by the DHS [Office of Program Integrity and Accountability \(OPIA\)](#), which is separate and independent from the Division:

- [Office of Licensing](#): Ensures adherence to regulatory standards for the operation of group homes, supervised apartments and community care residences.
- Field Safety and Services Unit: Performs unannounced [DHS Site Visits](#) twice per year to group homes, supervised apartments and community care residences in accordance with New Jersey statutes to assess whether individuals are at risk of, or are being subjected to abuse, neglect or exploitation.
- [Critical Incident Management Unit \(CIMU\)](#): Provides oversight in all matters related to incident reporting and the tracking, response and follow up to reported incidents.
- [Employment Controls and Compliance Unit](#): Performs background checks for the on-boarding processes for the hiring and continued employment of self-directed and agency employed staff working in programs providing services to persons with IDD.
- Incident Verification Unit: Performs in-person [verifications](#) of reported incidents and allegations involving injury, abuse, neglect and exploitation.
- [Office of Investigations \(OI\)](#): Performs civil investigations of serious allegations/incidents of abuse, neglect and exploitation and other serious incidents involving individuals receiving services through the Department.
- [Risk Management System](#): OPIA develops, collects and regularly reviews and evaluates specific performance indicators for providers of residential services using national and best practice guidelines. Please see [Office of Program Integrity and Accountability's Risk Indicator Report \(Data Dashboard\)](#) for more information.

It is required by law that all persons employed by, or volunteering in, any DHS-funded, licensed or regulated program, or a person providing services with in-direct State funding to an individual with IDD [report incidents or suspicions of abuse, neglect or exploitation](#). The Division maintains a toll-free number to call to report abuse, neglect or exploitation. That number is 1-800-832-9173 (then press 1). There is also an [FAQ on Reporting Abuse, Neglect or Exploitation](#) available. Reports can be made anonymously.

When a report of an incident is received, it is reviewed and categorized using OPIA's [Incident Reporting Levels and Categories Grid](#). Many types of incidents are considered reportable, such as physical and/or verbal abuse (either with or without injury); financial exploitation; existence of contraband at a residential or day program site; elopement; etc. Some incidents require follow-up and/or investigation. Depending on the type and severity of an alleged incident, an investigation may be assigned to either OPIA's [Office of Investigations](#) or [Critical Incident Management Unit](#).

Proactive Strategies

One of the most difficult realities for a family to contend is that there may likely be a time when they will need help with the care of their loved one with IDD. Many families have provided all care needs, including personal and medical care and are the “experts” on everything a caregiver must know to keep their loved one happy, healthy and safe. Transitions are often emotional and daunting for an individual with IDD as well as their family. The best outcomes occur when all parties recognize the need for trust and understanding to ensure the individual receives quality care. Creation of a partnership that promotes open communication and exchange of important information between the individual, family and provider helps avoid negative experiences for all involved.

For the purpose of this document, the focus of all parties is to prevent negative experiences from occurring. Therefore, following objectives are offered:

- Have clear, respectful, and transparent communication between the individual/guardian, their family/friends and the service provider;
- Have policies and procedures in place that prevent abuse, neglect, exploitation, and/or the experience of retaliation from occurring;
- Ensure that any incidents of alleged abuse, neglect, exploitation, and/or the experience of retaliation are reported.

Service Providers

A clear Communication Policy, aligning with state and federal rules¹, from the service provider is needed to aid in achieving the above objectives. This policy should be readily accessible to current/potential program participants and their family/guardian. Most importantly, the policy should clearly define how to report/escalate a concern. This includes, but may not be limited to:

- How general communication with **all** guardians, families and friends will occur – with emphasis on consistent implementation across programs so that differences in how circumstances are addressed can be identified;
- How, and to whom, an issue or concern related to individual care within the program the individual participates in is communicated;
- How, and to whom, an alleged concern/perception of retaliation is reported (even anonymously) within the service provider structure;
- What would trigger a discussion on changes related to communication. For example, directing interested persons to specific service provider staff for certain information updates;
- How to report an incident to the Division.

¹ This includes, but is not limited to: N.J.A.C. 10:44A, N.J.A.C. 10:44B, Day Habilitation Certification, Community Care Program and Supports Program Manuals, Home and Community Based Services Settings Rule, etc.

If a service provider does not have a Communication Policy readily accessible to families that includes the above areas the Division's Provider Performance and Monitoring Unit can provide technical assistance. They can be contacted at DDD.PPMU@dhs.nj.gov.

Families

For families interested in identifying a service provider, completing research can be helpful in understanding how a service provider operates, including how they interact with guardians and/or involved family members. While the Division and Support Coordinators are there to help, doing independent research on a potential provider will provide important information to aid in decision making and may help reduce anxiety. Some topics include, but are not limited to:

- Ask potential service providers how long they have provided services to individuals with IDD. This information may also be available on their website.
- Ask if the service provider has a list of families served by them who could be contacted to ask about their experience with services.
- Review public facing information about the service provider, such as the [Office of Program Integrity and Accountability's Risk Indicator Report \(Data Dashboard\)](#).
- Ask potential service providers about their experience serving individuals with needs similar to your family member. For example and as applicable, how many persons with behavioral health challenges or medical involvement they have successfully served and how they define success.
- Engage with the New Jersey Council on Developmental Disabilities [Regional Family Support Planning Councils](#) (RFSPCs). RFSPCs can help a family to engage with other families of individuals with IDD at a local level. This can provide a way to network with other families and obtain their perspectives based on their experiences.
- When engaging with potential service providers, explain the level of involvement you plan on having with your family member while being served by their agency. Ask for a copy of their policy handbook. Outline expectations related to medical oversight, information sharing, and other areas important to the individual/guardian/family. It is important for all parties have a clear understanding of expectations as early as possible.
- Ask potential service providers if they maintain credentialing through national organizations such as the [Council on Quality and Leadership](#) (CQL) or [Commission on Accreditation of Rehabilitation Facilities](#) (CARF).
- Ask about the bullet points in the *Service Provider* section of this document.

The Boggs Center on Developmental Disabilities, New Jersey's Center for Excellence in Developmental Disabilities Education, Research and Service has a helpful guidebook entitled [Selecting a Service Provider: Making Choices, Becoming Empowered](#). Persons engaging in a search for a service provider may find it useful.

After the selection of a service provider, further discuss individual preferences, communication and support needs at the person centered planning team meeting that occurs prior to the start of services. Be sure to include preferred communication methods between the individual, family, service provider, and any other planning team members.

If a family has already started receiving services and needs to report actual or suspected abuse, neglect, exploitation, and/or the fear or experience of retaliation they are directed to report it as described below. They are also free to inquire with the service provider about the bullet points in the *Service Provider* section of this document.

What do to if you determine you are experiencing retaliation?

To report actual or suspected abuse, neglect, exploitation, and/or the fear or experience of retaliation – call the Division at 1-800-832-9173 (then press 1). Reports can be made anonymously if that is the comfort level of the caller.

The Division will generate an incident report for all reportable incidents as described on page one of this document. If the incident is not reportable, but includes a clear allegation of retaliation, the Division's Provider Performance and Monitoring Unit will review and complete follow up with the individual/family/guardian and the service provider.