

8:43H-17.17 Facility finishes

(a) A rehabilitation hospital shall ensure that its facility complies with the following:

1. Cubicle curtains and draperies shall be noncombustible or rendered flame retardant;
 2. Floor materials shall be readily cleanable and wear-resistant for the location. Floors in food preparation or assembly areas shall be water-resistant. Joints in tile and similar materials in such areas shall also be resistant to food acids. In all areas frequently subject to wet cleaning methods, floor materials shall not be physically affected by germicidal and cleaning solutions. Floors subject to traffic while wet, such as shower and bath areas, kitchens, and similar work areas, shall have a non-slip surface;
 3. Wall bases in kitchens, soiled workrooms, and other areas that are frequently subject to wet cleaning methods shall be monolithic and covered with the floors, tightly sealed within the wall, and constructed without voids that can harbor insects;
 4. Wall finishes shall be washable and, in the proximity of plumbing fixtures, shall be smooth and moisture resistant. Finish, trim, and floor and wall construction in dietary and food preparation areas shall be free from spaces that can harbor pests;
 5. Floor and wall areas penetrated by pipes, ducts, and conduits shall be tightly sealed to minimize entry of pests. Joints of structural elements shall be similarly sealed; and
 6. Ceilings throughout shall be readily cleanable. All overhead piping and ductwork in the dietary and food preparation area shall be concealed behind a finished ceiling. Finished ceilings may be omitted in mechanical and equipment spaces, shops, general storage areas, and similar spaces, unless required for fire-resistive purposes.
- (b) Acoustical ceilings shall be provided for corridors in inpatient areas, nurses' stations, dayrooms, recreational rooms, dining areas, and waiting areas.

HUMAN SERVICES

(a)

BUREAU OF GUARDIANSHIP SERVICES

Guardianship Services

Proposed New Rules: N.J.A.C. 10:45

Authorized By: Sarah Adelman, Commissioner, Department of Human Services.

Authority: N.J.S.A. 30:1-12, 30:4-165-1.1, and 30:4-165.4 et seq., specifically 30:4-165.16.

Calendar Reference: See Summary below for explanation of the exception to the rulemaking calendar requirements.

Proposal Number: PRN 2024-078.

Submit comments by August 30, 2024, to:

Jessica Anastasi
 Bureau of Guardianship Services
 PO Box 705
 Trenton, NJ 08625-0705
 Fax: (609) 631-2215
 Email: Jessica.Anastasi@dhs.nj.gov
 Delivery: 11A Quakerbridge Plaza
 Mercerville, NJ 08619

The agency proposal follows:

Summary

N.J.A.C. 10:45, Guardianship Services, expired on June 4, 2018. The Department of Human Services (DHS) is proposing new rules, incorporating text from the expired rules with amendments, for the provision of guardianship services to individuals receiving services from the Division of Developmental Disabilities (DDD). These rules delineate guidelines for the provision of guardianship services by the Bureau of Guardianship Services (BGS) when acting as the court-appointed guardian of the person. The new rules are proposed to incorporate updates

of corresponding statutes and regulations regarding eligibility for services from DDD, add references to new services, and clarify BGS eligibility criteria.

The proposed new chapter includes the six subchapters described below.

Subchapter 1. General Provisions

This subchapter describes the authority of DHS to provide guardianship services to individuals receiving services from DDD and the assignment of those responsibilities by the Commissioner of DHS (Commissioner) to BGS, the guiding principles for BGS guardians, and definitions of terms used throughout the chapter.

N.J.A.C. 10:45-1.1 Authority

This section describes the authority of DHS to provide guardianship services to eligible individuals with an intellectual/developmental disability in accordance with N.J.S.A. 30:4-165.1. This section provides that BGS has been designated by the Commissioner to provide guardianship services, limiting those services to guardianship of the person in accordance with N.J.S.A. 30:4-165.12.

N.J.A.C. 10:45-1.2 Guiding Principles

This section provides the principles BGS guardians follow in the course of exercising their responsibilities, such as substitute decision-making and utilizing the best interest standard. Reasonable efforts will be made to promote and preserve the individual's human rights and maintain confidentiality. The purpose of these principles is to help secure the rights and wishes of individuals with developmental/intellectual disabilities and protect them from harm. This section provides clarifying language to explain the difference between substitute decision-making and the best interest standard. Both principles are used by BGS guardians. "End of life care" was referenced in the expired chapter, but is not included in the new rules because it is captured at N.J.A.C. 10:48B, Decision Making for the Terminally-Ill.

N.J.A.C. 10:45-1.3 Definitions

This section defines the words and terms that are used throughout this chapter.

Subchapter 2. Eligibility Requirements for Guardianship Services

This subchapter describes the eligibility requirements for adults to qualify to receive guardianship services.

N.J.A.C. 10:45-2.1 Eligibility for Adults

Individuals generally must be at least 21 years of age to be eligible to receive guardianship services from BGS. BGS no longer provides guardianship services for children, as this function was transferred to the Department of Children and Families (DCF). See N.J.S.A. 9:3A-9. However, for individuals between the ages of 18 through 21, BGS has the discretion to provide guardianship services to individuals currently receiving functional services from DCF when it is anticipated that the individual will transition to DDD services at the age of 21. See N.J.A.C. 10:46-2.1(i) (Upon reaching age 18, individuals may apply for DDD eligibility, but services will not begin until the individual reaches age 21).

Subchapter 3. Continuation of Eligibility for Guardianship Services

This subchapter describes the continuation of eligibility for adults who receive guardianship services.

N.J.A.C. 10:45-3.1 Continuation of Eligibility for Guardianship Services

This section describes under what circumstances guardianship services are continued for eligible adults after the initiation of services by BGS. An individual will remain eligible if they are not discharged from DDD services, receiving functional services from DDD, and/or the guardianship is not terminated by the court. This section addresses substitute guardianship, which occurs when a court appoints a new guardian and BGS is discharged as guardian.

Subchapter 4. Role and Responsibilities of BGS

This subchapter describes the role and functions of BGS guardians.

N.J.A.C. 10:45-4.1 Distinct Role of BGS Staff

BGS functions independently from any other division within DHS. BGS is charged with making reasonable efforts to select the most

appropriate course of action that is the least restrictive of the individual's freedom, rights, and ability to control the individual's environment. BGS staff is required to make reasonable efforts to build relationships with the individual; protect the individual from actual or potential injury, neglect, exploitation, undue influence, and abuse; safeguard the individual's rights; encourage the individual's participation in decision-making; encourage the individual to maintain contact with family; encourage and support the development of social relationships; contribute to the service plan; advocate for the provision of appropriate benefits and support services; protect the individual's privacy rights; and make decisions in accordance with the authority granted in the court order, including giving or withholding consent in major life areas up to and including making end-of-life decisions. This section also references the Human Rights Committee (HRC) in relation to the roles of BGS, DDD, and the service components. The HRC reviews proposed consumer restrictions and alleged consumer rights violations. BGS, where appropriate, will request that DDD, or the service component staff, make referrals to the HRC when issues arise.

N.J.A.C. 10:45-4.2 Functions and Duties of BGS Staff

This section describes the functions and duties of BGS guardians with regard to communication, meetings, interviews, and obtaining the most current information about the individual. Guardians are also responsible for the preparation of a report of their findings and recommendations.

Subchapter 5. Limitations of BGS Authority

This subchapter sets forth the scope of BGS authority and provides the areas in which court approval must be obtained before consent can be given for the provision of the procedures specifically referenced in the rule.

N.J.A.C. 10:45-5.1 Procedures Requiring Court Approval

This section provides that, in accordance with N.J.S.A. 30:6D-5.a, BGS staff cannot consent to the following procedures: shock treatment (Electroconvulsive Therapy or ECT); psychosurgery; sterilization; or experimental medical, behavioral, or pharmacological research. BGS staff, with the approval of the BGS Bureau Chief, may refer such decisions to a court of competent jurisdiction for appointment of a *guardian ad litem*. Research proposals shall be referred to DDD's Interdisciplinary Research Committee (IRC) before being referred to a court. Exceptions to the need for court-ordered *guardian ad litem* include off-label use of medications where recommended by a physician or psychiatrist and deemed appropriate for treatment of a specific condition. A court-appointed *guardian ad litem* is not required for individuals receiving medical treatments that could result in infertility. Additionally, non-invasive research, such as information gathering and surveys, is permissible without court approval.

N.J.A.C. 10:45-5.2 Other Limitations and Specific Considerations of BGS Authority

This section clarifies areas of special consideration when making decisions. While BGS is prohibited from serving as a guardian of an estate, BGS may make certain financially related decisions, including signing leases and residency agreements, establishing burial funds, assisting in establishing ABLE (Achieving a Better Life Experience Act) accounts or pooled trusts, consulting with a trustee or agency, and providing guidance regarding spending or managing individual funds. BGS does not serve as representative payee but, as guardian of a person, BGS shall have authority to request a change in the Social Security representative payee, as needed.

BGS will seek to redact hold harmless clauses often included on consent forms that BGS reviews. If a redacted form is not accepted and the individual will be excluded from the activity or service as a result, BGS may consider consenting when weighing the risk of inclusion of such a clause.

BGS will use discretion when considering when to consent to voluntary admission for mental or behavioral health treatment at a hospital or other facility that offers inpatient services, taking into consideration the individual's wishes, history, experience, risks, and benefits of such treatment versus the risk of forgoing the treatment, and subject to the requirements of New Jersey Court Rule 4:74-7, when applicable.

BGS may not consent to surrender the parental rights of a child of an individual it serves. If there is cause to terminate an individual's parental rights, due process will occur through a court proceeding. BGS does not take a position on termination of parental rights, unless requested by the incapacitated person.

BGS may consent to procedures that are medically necessary to treat any health condition even where the treatment may result in infertility, as long as the treatment is not specifically intended for sterilization. This includes consenting to treatment for reproductive health conditions, as well as birth control for the prevention of pregnancy.

BGS has the discretion to act in a temporary guardianship capacity for an individual. However, BGS is not permitted, under any circumstances, to act as guardian of property.

Subchapter 6. Responsibilities of Service Component to Inform BGS

This subchapter outlines the duties of service providers to inform BGS of any significant life events of the individual under guardianship.

N.J.A.C. 10:45-6.1 Duty to Inform BGS

This section describes the responsibility of service providers to promptly inform BGS guardians of any significant life changes, proposed changes to the residence or program, or unusual incidents involving individuals served by BGS. Failure to notify BGS will be considered a violation of the individual's rights and reportable as an unusual incident.

As DHS has provided a 60-day comment period for this notice of proposal, this notice is excepted from the rulemaking calendar requirement in accordance with N.J.A.C. 1:30-3.3(a)5.

Social Impact

As of January 2023, guardianship services were being provided by BGS to approximately 2,200 individuals. The proposed new rules set forth the role of BGS when acting as the court-appointed guardian of an individual with a developmental/intellectual disability who is eligible for and receiving services from DDD.

The proposed new rules help ensure that the State, through BGS, acts as guardian of the person for such individuals when there is no other appropriate party willing or able to serve as the guardian. The rules allow for guardianship services without financial expense to the person served or their family. The new rules are proposed to formalize the policy and practice of BGS to exercise decision-making authority on behalf of an incapacitated person only in those areas where the individual lacks the ability to make their own decisions.

Economic Impact

It is anticipated that the proposed new rules will have a positive impact on the families of individuals served by DHS. The rules ensure that guardianship services are provided when there is no interested party willing or able to fulfill that function on behalf of an individual. There is no fee imposed on families when DHS provides guardianship services.

BGS will incur the most significant economic impact of the proposed new rules. Staff resources are utilized to gather the information needed for decision-making, as well as any information necessary for the preparation of court documents, including a clinical assessment, and documents needed to amend the guardianship that may be required by the court. BGS contracts with clinicians to complete guardianship assessments. Currently, this cost is budgeted, and BGS also has a funding agreement with the Office of the Public Defender (OPD) to represent individuals with intellectual/developmental disabilities in guardianship matters. The need for representation by the OPD includes petitions for substitute guardianship.

The new proposed rules are not expected to have any economic impact on providers of services.

Federal Standards Statement

A Federal standards analysis is not required because the proposed new rules are not subject to Federal requirements or standards.

Jobs Impact

The proposed new rules governing guardianship services will not generate jobs or cause jobs to be lost.

Agriculture Industry Impact

The proposed new rules will have no impact on agriculture in the State of New Jersey.

Regulatory Flexibility Statement

A regulatory flexibility analysis is not required because the proposed new rules do not impose any new reporting, recordkeeping, or other compliance requirements upon small businesses, as defined pursuant to the Regulatory Flexibility Act, N.J.S.A. 52:14B-16 et seq. As the proposed new rules apply only to individuals served by DDD, any effect on small businesses or private industry in general would be minimal. Community care providers and other service providing agencies that meet the definition of a small business are required to report significant life changing events of individuals who receive BGS services. This is not a new requirement, would not require the hiring of professional services, and is necessary for the health, safety, and welfare of the individual receiving services. Accordingly, a regulatory flexibility analysis is not needed.

Housing Affordability Impact Analysis

The proposed new rules will not have a significant impact on the affordability of housing and are not likely to have an effect on the average costs associated with housing in New Jersey. The rules proposed govern guardianship services and concern decision-making for individuals receiving services from DDD.

Smart Growth Development Impact Analysis

The proposed new rules will not have a significant impact on smart growth and there is an extreme unlikelihood that the rules will evoke a change in housing production in Planning Areas 1 or 2, or within designated centers, pursuant to the State Development and Redevelopment Plan in New Jersey because the rules govern guardianship services and concern decision-making for individuals receiving services from DDD.

Racial and Ethnic Community Criminal Justice and Public Safety Impact

The proposed new rules will not have an impact on pretrial detention, sentencing, probation, or parole policies concerning juveniles or adults in the State. Accordingly, no further analysis is required.

Full text of the proposed new rules follows:

CHAPTER 45
GUARDIANSHIP SERVICES

SUBCHAPTER 1. GENERAL PROVISIONS

10:45-1.1 Authority

(a) The Department of Human Services (DHS) is directed to provide comprehensive services, specifically including guardianship services, to eligible individuals with an intellectual/developmental disability, in order that they may be provided with adequate training, care, and protection pursuant to N.J.S.A. 30:4-165.1.

(b) DHS is directed to perform such services for adults who are incapacitated, for whom no guardian has been appointed, and which would otherwise be rendered by a guardian of the person pursuant to N.J.S.A. 30:4-165.5.

(c) The Bureau of Guardianship Services (BGS) has been assigned the responsibility of providing guardianship services by the Commissioner. Guardianship services are limited to guardianship of the person only and not guardianship of property pursuant to N.J.S.A. 30:4-165.12.

10:45-1.2 Guiding principles

(a) BGS guardians shall be guided by the following principles when exercising their responsibilities:

1. Guardianship is a legal relationship in which an individual or entity is legally authorized to make decisions on behalf of another individual to the extent determined by a court of competent jurisdiction and specified in a court order issued by that court;

2. BGS is permitted by law to serve as guardian of the person only. In this role, BGS is the individual's personal representative, as well as the individual's advocate and legally authorized decision-maker;

3. BGS will use the principles of substitute decision-making and apply the best interest standard to its practices. Determining the individual's preferences and wishes are paramount. Consistent with the guiding principles of guardianship practices, a balanced approach is necessary and the best interest standard will be applied, when necessary, for the health and safety of the individual;

4. Decisions made in one area of an individual's life often affect other areas of the individual's life. Therefore, the BGS guardian should be notified, in advance, of decisions to be made in areas in which the individual retains decision-making authority. The individual should be given the opportunity to consult with the BGS guardian in all areas of his or her life and to request that the BGS guardian provide assistance in advocating for his or her wishes;

5. Surrogate decision-making should be based upon the principle of informed consent, giving due respect to the wishes, preferences, and self-determination of the individual while balancing the individual's need for protection from harm;

6. Reasonable efforts should be made to promote and preserve the individual's human rights, including the right to privacy, dignity, respect, and self-determination, pursuant to N.J.S.A. 30:6D-1 et seq., and in accordance with N.J.A.C. 10:41A;

7. Maintaining confidentiality is an essential component of the right to privacy. Therefore, only information necessary and relevant to the issue being addressed should be disclosed;

8. Reasonable efforts should be made to maximize opportunities for decision-making and the development of individual skills, as both are necessary components for enhancing self-direction and independence. The goal, if possible, should be to restore the individual to capacity, either full or limited;

9. It is important to determine the extent to which the individual identifies with particular ethnic, religious, and cultural values, and to respect those values when making decisions on behalf of the individual. Further, opportunities for the expression of those values should be respected and supported;

10. The individual should receive the highest quality of care available. Reasonable efforts should be made to protect and nourish the dignity of the individual and to carefully weigh the benefits and burdens of treatment when considering what is in the best interest of the individual. End-of-life decisions shall be made in accordance with N.J.A.C. 10:48B; and

11. Individuals receiving guardianship services have a right to interpersonal relationships and sexual expression, as long as the latter is consensual in nature, the individual is not victimized, and an environment suitable to this expression is provided. Individuals have a right to marry, but prior to entering the marriage, further review by the court may be required in accordance with the judgement of guardianship.

10:45-1.3 Definitions

The following words and terms as used in this chapter shall have the following meanings, unless the context clearly indicates otherwise.

"Assistant Commissioner" means the Assistant Commissioner of the Department of Human Services Office of Legal and Regulatory Affairs.

"Best interest standard" is the standard by which decisions are made when the individual's wishes cannot be determined, when following the individual's wishes would cause substantial harm to the individual, or when the guardian is unable to establish the individual's prior or current wishes.

"Bureau of Guardianship Services" or "BGS" means the unit within the Department of Human Services (DHS) that the Commissioner has designated to exercise the Commissioner's responsibility and authority to provide guardian of the person services to individuals receiving DDD services who are in need of a surrogate decision-maker as determined by the court.

"Capacity" means the ability to employ the appropriate reasoning relative to the demands of the decision to be made. An individual may have capacity for decision-making in some areas of life, but not for the others, or for some decisions within an area of life, but not all.

"Commissioner" means the Commissioner of the Department of Human Services.

"Disability Rights New Jersey" or "DRNJ" means the organization designated by the Governor to be the agency to implement, on behalf of

the State of New Jersey, the Protection and Advocacy System established pursuant to the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §§ 15041 through 15045.

“Division” or “DDD” means the Division of Developmental Disabilities.

“Ethics Committee” means a multi-disciplinary committee, independent of the Division and recognized by the Department Assistant Commissioner of Legal and Regulatory Affairs, or their designee, in accordance with N.J.A.C. 10:48B-2.1 that shall have a consultative role in reviewing critical areas of decision-making when BGS is the guardian.

“Family” means spouse, domestic partner as defined at N.J.S.A. 26:8A-3, children, parents, and siblings of the individual alleged to be in need of a guardian.

“Functional or other services” means those services and programs in the Division that are available to provide the individuals with developmental disabilities with education, training, rehabilitation, adjustment, treatment, care, and protection. Functional or other services shall include residential care; support coordination or case management; and supervision of day-to-day activities such as: activities of daily living, social, leisure, or structured programs, and day programming.

“Guardian” means an individual or agency appointed by a court of competent jurisdiction or who is otherwise legally authorized and responsible to act on behalf of a minor or incapacitated adult to ensure provision for the health, safety, and welfare of the individual and to protect their rights consistent with N.J.S.A. 3B:12-57 and 30:4-165.1 et seq., and the judgment of guardianship.

“Guardian ad litem” means an individual appointed by a court to perform a limited type of guardianship to protect a child’s or incapacitated adult’s interest during a single instance of some form of court proceedings or litigation.

“Guardian of the person” means an individual or agency appointed by a court of competent jurisdiction to make personal decisions in some or all decision-making areas of an individual’s life, excluding decisions about an individual’s property.

“Guardianship services” means those services and programs provided by DHS for the purpose of implementing its responsibility toward the individual with developmental disabilities for whom it is performing the services of guardian of the person.

“Incapacitated individual” means an adult individual who is impaired by reason of mental illness, mental deficiency, physical illness, or disability, chronic use of drugs, chronic alcoholism, or other cause to the extent that the person lacks sufficient capacity to govern himself or herself and manage their affairs.

“Individual” means a person receiving services from DDD and where BGS has been appointed as guardian of the person through adjudication by the court.

“Informed consent” means a process of decision-making based upon an understanding of the proposed action or treatment, risks, benefits, alternatives, and possible outcomes.

“Intellectual/developmental disability” means a severe, chronic disability as defined at N.J.A.C. 10:46-1.3.

“Interdisciplinary Team” or “IDT” means a group that consists of the individual receiving services, the plan coordinator, the legal guardian, the Division case manager and/or support coordinator, the parents or family member(s) (if the adult who has not been adjudicated incapacitated desires that the parent or family member be present), advocates and friends, those persons who work most directly with the individual served, as well as professionals and representatives of service areas who are relevant to the identification of the individual’s needs and the design and evaluation of programs to meet them. The individual or their guardian may identify those additional persons the individual wishes to be present.

“Interested party” means anyone involved in the life of an adult that might have input into the decision being rendered. An interested party includes, but is not limited to, family, provider staff, medical staff, or team members from the IDT.

“Least restrictive” is the principle of seeking solutions that are the least restrictive and intrusive to an individual’s liberty and that preserve, to the maximum extent possible, the individual’s autonomy while providing needed protections.

“Service component” means any developmental center, community services office of the Division, Support Coordination Agency, DDD day program, or residential facility.

“Service plan” means a written, individualized habilitation plan, consistent with the requirements at N.J.S.A. 30:6D-10 through 12, developed with the individual and/or their legal guardian, and the IDT. It is an outcome-based planning tool that, at a minimum, identifies each individualized program, support, and/or service requested by and provided to the individual, for which the individual demonstrates a need. It identifies the person and/or private agency responsible for its implementation. The complexity of the service plan will vary according to the individual’s interests, preferences, and needs. The format of the service plan may vary in accordance with the requirements of the specific program, service, or support received by the individual.

“Substitute judgment” is the principle of decision-making that substitutes, as the guiding force in any surrogate decision made by the guardian, the decision the individual would have made when competent. Substitute judgment promotes the underlying values of self-determination and well-being of the individual.

SUBCHAPTER 2. ELIGIBILITY REQUIREMENTS FOR GUARDIANSHIP SERVICES

10:45-2.1 Eligibility requirements for adults

(a) An individual 21 years or older is eligible for guardianship services if they have been formally determined by the Division to be eligible for services, is receiving functional services from the Division, and has been adjudicated as an incapacitated individual by a court of competent jurisdiction, where BGS has submitted an acceptance of guardianship, and the individual has had BGS appointed by the court as guardian of the person.

(b) Notwithstanding the provisions at (a) above, every individual receiving guardianship services from BGS without prior judicial review shall be reevaluated pursuant to N.J.S.A. 30:4-165.13 to determine whether the need for such services continues to exist and, if so, application shall be made to a court of competent jurisdiction for appointment of a guardian of the person for that individual.

(c) Notwithstanding the provisions at (a) above, the BGS Bureau Chief may serve as guardian of an individual between the ages of 18 through 21 who has been determined eligible for services from the Division but is receiving functional services from the Department of Children and Families (DCF) until such time that functional services will be provided by DDD where no other family or interested party is available or appropriate to serve as guardian of the person.

SUBCHAPTER 3. CONTINUATION OF ELIGIBILITY FOR GUARDIANSHIP SERVICES

10:45-3.1 Continuation of eligibility for adults

(a) Eligibility for guardianship services continues for an adult individual, as long as:

1. The individual remains a recipient of services from the Division; and
2. None of the following has occurred:
 - i. A court order reversing a previous adjudication of incapacity and appointment of BGS as guardian;
 - ii. A court order modifying the guardianship or appointing a substitute guardian in place of BGS; and
 - iii. Death of the incapacitated individual. BGS is discharged upon death of a person served, except for limited authority after death for such things as arranging for burial, organ donation, and reporting to the surrogate.

SUBCHAPTER 4. ROLE AND RESPONSIBILITIES OF BUREAU OF GUARDIANSHIP SERVICES

10:45-4.1 Distinct role of BGS staff

(a) BGS staff shall function distinctly and independently from the service components and shall maintain independent decision-making from the service components.

(b) The needs of the individual are paramount, therefore, BGS shall make reasonable efforts to select the most appropriate course of action

that is the least restrictive of the individual's freedom, rights, and ability to control their environment. To that end, BGS staff shall make reasonable efforts to:

1. Build a relationship with the individual, to the extent possible, that is based upon mutual respect and trust in order to advocate for what the individual wants or be able to make decisions in the best interest of the individual should the individual be unable to express his or her wishes;
2. Protect the individual from actual or potential injury, neglect, exploitation, undue influence, and abuse. BGS staff will, where appropriate:
 - i. Report suspicions to appropriate Division staff;
 - ii. Initiate an Unusual Incident Report (UIR);
 - iii. Provide input into investigations;
 - iv. Advocate for needed interventions; and
 - v. Initiate legal action;
3. Safeguard the individual's rights in accordance with statutes, rules, and case law. BGS will, where appropriate:
 - i. Inform the individual of his or her rights and responsibilities;
 - ii. Explain the content and meaning of the guardianship court order;
 - iii. Advocate with appropriate staff;
 - iv. Initiate an Unusual Incident Report;
 - v. Request DDD or the service component staff to refer potential violations of individual rights to their Human Rights Committee, as defined at N.J.A.C. 10:41A-1.3, if other levels of resolution have been exhausted; and
 - vi. Consult with outside sources including, but not limited to:
 - (1) Ethics committees;
 - (2) Disability Rights New Jersey;
 - (3) Law enforcement agencies; and
 - (4) Legal consultation and representation;
4. Encourage the individual's participation in decision-making by:
 - i. Seeking the wishes of the individual;
 - ii. Giving due respect to the individual's wishes;
 - iii. Advocating for the individual's wishes;
 - iv. Recognizing and/or developing opportunities for decision-making; and
 - v. Encouraging/promoting self-reliance, independence, self-care, and self-advocacy;
5. Make decisions in accordance with the authority granted in the court order utilizing the principle of informed consent and in consideration of the individual's identification with particular ethnic, religious, and cultural values. In evaluating a requested action or treatment, the guardian will incorporate the following, as appropriate:
 - i. Review the nature of the requested action or treatment;
 - ii. Gather adequate information on the issue by using available resources including, but not limited to:
 - (1) Search the Internet;
 - (2) Read books and articles; and
 - (3) Consult with experts in the field;
 - iii. Gather needed reports;
 - iv. Discuss the proposed action or medical treatment with involved professionals;
 - v. Seek input from the individual, family, and caregivers;
 - vi. Explore possible alternatives;
 - vii. Explain the proposed action or treatment and possible alternatives to the individual in the presence of family, involved professionals, and caregivers, when possible;
 - viii. Seek the voluntary assent of the individual;
 - ix. Ensure that the individual's assent is free of coercion;
 - x. Weigh the risks, benefits, alternatives, and anticipated outcomes of proposed action or treatment;
 - xi. Refer to an ethics committee, if needed;
 - xii. Give or withhold consent using substitute judgment;
 - xiii. Give or withhold consent using the best interest standard;
 - xiv. Communicate the decision to the individual, involved professionals, family, and caregivers; and
 - xv. Evaluate the outcome of decision;
6. Encourage the individual to maintain contact with his or her family, as well as respect and support the individual's wishes regarding contact

with family unless such contact is not in the best interest of the individual. Where appropriate, the guardian will engage in the following:

- i. Discuss family contact with the individual during the annual visit;
 - ii. Discuss family contact at the service plan meeting; and
 - iii. Facilitate family contact at the request of the individual;
7. Encourage and support the development of social relationships that contribute to the well-being of the individual by:
 - i. Advocating for opportunities for positive social interaction;
 - ii. Taking steps, where applicable, to determine the individual's capacity for consensual sex; and
 - iii. Taking steps, where applicable, to provide the needed education and information for the individual to exercise the right of sexual expression, including information about marriage, interpersonal relationships, sexual health, birth control, and assistance in choosing the most appropriate form of birth control;
 8. Contribute to the service plan by:
 - i. Representing the individual at the service plan meeting through personal attendance or by providing written or verbal suggestions/recommendations prior to the meeting, if unable to attend;
 - ii. Encouraging the individual's participation at the meeting;
 - iii. Reviewing the completed service plan and provide written input, as needed;
 - iv. Reviewing decisions made by the individual during the year;
 - v. Reviewing the individual's understanding of guardianship;
 - vi. Reviewing the individual's perception of his or her need for guardianship;
 - vii. Reviewing the appropriateness of guardianship;
 - viii. Recommending a referral to the psychologist for guardianship assessment, as needed;
 - ix. Recommending, as applicable, that the individual be provided with needed education and information;
 - x. Advocating for a burial plan to be included in the service plan; and
 - xi. Giving or withholding approval for the service plan;
 9. Making end-of-life decisions, in accordance with N.J.A.C. 10:48B; and
 10. Protecting the individual's right to privacy by:
 - i. Giving or withholding consent for release of confidential information, including protected health information in accordance with the Health Insurance Portability and Accountability Act (HIPAA), 45 CFR Parts 160 and 164;
 - ii. Giving or withholding consent for photographing the individual if the photograph is to be used for display or public dissemination, in accordance with N.J.A.C. 10:41-3.3;
 - iii. Giving or withholding consent for audio taping and videotaping the individual other than for treatment purposes or health care operations, in accordance with N.J.A.C. 10:41-3.3; and
 - iv. Consent for photographs, audio taping, and videotaping for any public purpose, including social media posts, shall be contingent on the individual's willingness to participate.
- (c) In accordance with the individual's human rights and the authority granted in the court order, BGS staff shall have the responsibility and authority to act in areas that include, but are not limited to:
1. Reviewing the adequacy of the services being provided;
 2. Communicating with interested parties especially family, caregivers, and staff regarding the status, needs, and wishes of the individual;
 3. Providing or withholding consent for any change in residence or program, transfer, or discharge;
 4. Providing or withholding consent for elective medical or dental procedures that require specific authorization, as well as the general consent sufficient for routine medical or dental care;
 5. Providing or withholding consent for the use of behavior support plans with identified behavior risk elements;
 6. Providing or withholding consent for the service plan;
 7. Providing or withholding consent for the release of records or other confidential information and for the publication of photographs, newspaper articles, books, etc., which identify the individual;
 8. Providing or withholding consent for the use of psychotropic medication as part of an ongoing treatment plan to address maladaptive behavior; and

9. Providing or withholding consent for visits, vacations, trips, or other absences from the residence or day program. General permission may be granted for recurring absences with parents, family members, or other approved individuals.

10:45-4.2 Functions and duties of BGS staff

(a) In order to exercise their role and responsibilities, BGS staff shall be knowledgeable and informed about the individual's status, program, and progress by means of the following:

1. Meeting with the individual at least once a year including individuals in out-of-State purchase of care facilities within a one-day driving distance from the BGS staff's assigned office;

2. Meeting the individual at least once every three months, if the individual is not visited by representatives from any other public or private agency, or as designated by the Bureau Chief or Assistant Bureau Chief pursuant to N.J.S.A. 3B:12-57.f(2);

3. Reviewing the appropriate records including, but not limited to, the DDD records, medical records, community care residence or residential provider records, and other provider agency records;

4. Interviewing collateral staff including, but not limited to: case manager, support coordinator, community care residence or residential provider, and other provider agency staff;

5. Maintaining regular contact with interested and/or involved family through attendance at IDT meetings, personal meetings, phone calls, and correspondence;

6. Maintaining an ongoing written record of actions taken on behalf of the individual;

7. Preparing a report pertaining to the health and well-being of the individual; and

8. Sharing recommendations from the report with the service component.

(b) BGS shall maintain a file for each individual. The file must contain the following:

1. An ongoing written record of actions taken on behalf of the individual;

2. An annual report pertaining to the health and well-being of the individual; and

3. Recommendations that have been shared with the service component.

SUBCHAPTER 5. LIMITATIONS OF BGS AUTHORITY

10:45-5.1 Procedures requiring court approval

(a) Pursuant to N.J.S.A. 30:6D-5.a(4), BGS staff shall not consent to the following procedures but may, with the approval of the Bureau Chief, refer the matter to a court of competent jurisdiction for appointment of a *guardian ad litem*:

1. Shock treatment (ECT);
2. Psychosurgery;
3. Sterilization; or
4. Medical, behavioral, or pharmacological research as experimentation.

i. Research proposals shall be referred to DDD's Interdisciplinary Research Committee (IRC) before being referred to the court.

(b) Exceptions to the need for a court ordered *guardian ad-litem*:

1. On a case-by-case basis, with the approval of the Bureau Chief or his or her designee, BGS may provide consent to medically recommended off-label use of medication or non-FDA approved drugs or treatment where other medications or treatments are not effective and the drug or treatment is not being prescribed for the purposes of pharmacological experimentation; and

2. Consent may be provided on a case-by-case basis for non-invasive research, such as information gathering, surveys, or study groups that do not fall into the category of pharmacological experimentation.

10:45-5.2 Other limitations and specific considerations of BGS authority

(a) BGS is prohibited from serving as guardian of an estate and may not receive funds or consent to the sale of real property (that is, a home, land). However, BGS has authority to provide consent to the following

property-related matters when consistent with the areas of guardianship authority:

1. BGS may sign residency agreements or leases as a legal or residential decision on behalf of a person served, but BGS is not responsible for the lessee's debt;

2. BGS may establish an irrevocable, pre-paid burial trust as guardian of legal matters and may direct funds from the payee, executor, or other institution, directly into the trust;

3. BGS may consent to the establishment of a pooled trust or Achieving a Better Life Experience Act (ABLE) account consistent with Medicaid rules;

4. BGS may provide input to a trustee regarding the need for or justification of a purchase being made from a special needs trust or other such trust; and

5. BGS may request a change in the Social Security representative payee and provide input and approval of a budget established by a Social Security representative payee in the best interest of an individual.

(b) When possible, BGS will redact hold harmless or waiver of liability clauses commonly found on consent forms. If a redacted form is not accepted and the individual will be excluded from the activity or service as a result, BGS may consider consenting when weighing the risk of inclusion of such a clause.

(c) BGS will use discretion when considering when to consent to voluntary admission for mental or behavioral health treatment at a hospital or other facility that offers inpatient services, taking into consideration the individual's wishes, history, experience, risks, and benefits of such treatment versus the risk of forgoing the treatment, and subject to the requirements of New Jersey Court Rule 4:74-7, when applicable.

(d) BGS does not have authority to sign a voluntary surrender of parental rights to a child born to a person BGS serves. If there is cause to terminate a BGS client's parental rights, due process will occur through Division of Child Protection and Permanency legal proceedings.

(e) Consent may be granted for a medically necessary procedure that may result in infertility but is not being done for the purposes of sterilization. BGS may consent to temporary or short-term birth control as part of general medical decision-making.

(f) At the Bureau Chief's discretion, BGS may serve as temporary guardian of the person, where the individual is DDD eligible and receiving DDD functional services. However, BGS remains prohibited from serving as guardian of property in all circumstances.

SUBCHAPTER 6. RESPONSIBILITY OF SERVICE COMPONENT TO INFORM BGS

10:45-6.1 Duty to inform BGS

(a) The service component staff, community care providers, and provider agency staff shall inform BGS staff promptly and comprehensively regarding any significant life events, proposed changes to residence or program, or unusual incidents involving individuals being served by BGS including, but not limited to, the following areas:

1. Medical, as follows:

i. Changes in an individual's medical, psychiatric, behavioral, or emotional status;

ii. Changes in prescribed medication;

iii. Additional diagnoses identified;

iv. Hospitalizations; and

v. Significant or new specialist's appointments/consultations;

2. Service plans and meetings, as follows:

i. The service plan may vary dependent upon the setting in which an individual lives or the types of services they receive. The guardian should be consulted for mutually convenient dates when scheduling service plan or emergent meetings;

ii. A minimum of two weeks notification of the required annual service plan meetings at developmental centers;

iii. Community-based service plan meetings require a minimum of five days advance notice of the confirmed meeting date, time, and location; and

iv. Special IDT meetings may be necessary to address individual concerns. Advanced notice of IDT meetings along with the nature of the issue being discussed, will be provided;

- 3. Program changes, as follows:
 - i. Unless emergency circumstances apply, advance notice of any proposed program changes is required in order for the guardian to consent or withhold consent. Program changes include changes in residence, day program, support services, and/or transfer or discharge;
 - ii. If a temporary change is necessary due to a physical plant issue (for example, no hot water), notification must be made to the guardian as soon as possible;
 - iii. Advanced notice of proposed respite placement will be provided; and
 - iv. Problems or changes in residence or program including, but not limited to:
 - (1) Behavior problems;
 - (2) Emergency respite placement; or
 - (3) Chronic absenteeism;
- 4. Family, as follows:
 - i. Family concerns/issues;
 - ii. Changes in family information; and
 - iii. Reappearance of family;

- 5. Unusual incidents; and
 - 6. Changes in case manager or support coordinator.
- (b) Service component, community care provider, and agency staff shall advise BGS of the following as soon as possible, but no later than within one working day:
- 1. Clinical conclusion that the individual no longer needs a guardian;
 - 2. Request of an individual to see his or her BGS guardian;
 - 3. Missing status or failure to return from vacation;
 - 4. Alleged or suspected abuse, neglect, exploitation, or denial of rights;
 - 5. Serious illness or injury;
 - 6. Emergency placement or respite; and
 - 7. Death, including circumstances, cause, results, or investigation, if any.
- (c) Failure to notify BGS of events listed at (a) and (b) above, shall be considered a violation of the individual's rights and, therefore, reportable as an unusual incident.
