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Applicability: DDSN Operated Programs (DDSN Regional Centers and Autism Programs), DSN Boards and Contracted Services Providers

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## **PURPOSE**

This directive establishes guidelines for the involvement of the parents, legal guardians, or family representatives in the development and delivery of services by the Department of Disabilities of Special Needs (DDSN) Operated Programs, DSN Boards and contracted service providers. Additionally, this directive presents a summary of issues that deal with involvement and interaction with families whose members are being served by DDSN.

## **STATEMENT OF PHILOSOPHY**

Individuals with disabilities are people first and have the same rights as others. Like most families, direct parental/family involvement in the making of major life decisions will vary in relation to the age and the abilities of the individual. Parents/legal guardians of service recipients in their minority years are expected to assert more control and direction than are the parents of adult service recipients. Individuals with limited experience and knowledge sometimes need training and support in order to make appropriate choices and exercise rights throughout their lives.

### **DISTRICT I**

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Clinton, SC 29325-5328  
Phone: (864) 938-3497

Midlands Center - Phone: 803/935-7500  
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9995 Miles Jamison Road  
Summerville, SC 29485  
Phone: 843/832-5576

### **DISTRICT II**

Coastal Center - Phone: 843/873-5750  
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Families, friends and close associates provide vital supports in preparing individuals to exercise rights and assume responsibilities. Increasing competence in decision-making is a life-long process, which is enhanced by interaction with and support from the people closest to us.

Parental/family involvement and participation in all aspects of service delivery for individuals with disabilities is most often a normal, appropriate and desirable course. The individual receiving service's welfare, growth and happiness are the mutual responsibility and concern of the service recipient himself/herself, the family, DDSN (the Agency and Operated Programs), DSN Boards and contracted service providers.

DDSN will support the family unit and, whenever possible and appropriate, individuals will be served as close to their family and home communities as possible.

Families are encouraged to maintain contact and involvement with their family member. Family involvement and participation with DDSN Operated Programs, DSN Boards, and contracted service providers in planning will facilitate decisions that serve the best interests and welfare of those who receive services.

### **CONSUMER RESPONSIBILITIES**

To the extent adults receiving services are competent to plan and direct their lives; they bear responsibility for their own happiness and success. Therefore, to the fullest extent possible, they should receive the training, experience and opportunity to make decisions and exercise rights.

Applicants will be invited and encouraged to participate in the eligibility determination process by assisting in obtaining needed medical, educational, and social information. If the applicant is not eligible for services with DDSN, then information about other service(s) will be provided as appropriate.

For those service recipients who are either still in their minority years or who are not capable of planning and directing their lives without support, parents/legal guardians play a critical role in decision making.

When an individual receiving services is deemed to need a guardian or other substitute decision maker, assessments should be done to determine the service recipient's specific range of abilities with regard to decision making so that guardianship or substitute decision-making does not extend beyond the areas needed. Furthermore, the need for guardianship or substitute decision-making should be periodically reviewed.

Decision-making should be returned to the service recipient if improvement in skills or a change in personal situation occurs over time. Although guardianship or substitute decision-making puts legal limits on the service recipient's exercise of certain rights, it does not prevent the individual from participating in and influencing decisions or exercising other rights. For more information, please see DDSN Directive 535-07-DD: Obtaining Consent for Minors and Adults.

## **FAMILY RESPONSIBILITIES**

Families are encouraged and expected to participate actively in the learning, growth, and development process of their family member. Such involvement begins during DDSN's eligibility determination and, if eligible, continues through service provision.

Parents/guardians/family representatives will be invited and encouraged to participate in the eligibility determination process by assisting in obtaining needed medical, educational, and social information. If determined not eligible for services with DDSN, information about other service(s) will be provided as appropriate. With the concurrence of adult service recipients, families should participate in meetings involving the individual, keep DDSN or the DSN Board/contracted service provider informed of any programmatic, medical or financial changes that might affect the status of the service recipient and work with the service provider to ensure that appropriate services and supports are being provided.

Families are encouraged to become involved in organizations that provide support for and promote understanding among families, and are a forum for exchange of information and ideas among DDSN, DSN Boards/contracted service providers and families.

If it becomes necessary or appropriate for placement in a community residential alternative or DDSN Operated Program, families are encouraged, as appropriate, to maintain active involvement through visitation and other forms of contact. Families should participate in service planning meetings, monitor the service recipient's progress, and actively participate in the service recipient's life planning as appropriate.

## **DDSN OPERATED PROGRAMS, DSN BOARD AND CONTRACTED SERVICE PROVIDER OBLIGATIONS AND RESPONSIBILITIES**

The family is an integral part of an individual's life and with the concurrence of the adult service recipient, DDSN Operated Programs and DSN Boards/contracted service providers shall, as appropriate, support and encourage a continuing relationship with all families. To facilitate this, within available resources, support services will be developed which assist families in managing and maintaining their family member in their own home as long as may be desirable.

DDSN Operated Programs and DSN Boards/contracted service providers will work with local Departments of Social Services and/or courts to involve families to the extent possible when their family member is under court order or protective services.

For those individuals without any family involvement, DDSN Operated Programs and DSN Boards/contracted service providers should develop family/volunteer contacts to assist the service recipient where necessary in advocating for his/her program needs.

DDSN and DSN Boards/contracted service providers will facilitate family involvement in the following ways:

### Orientation For Individuals Entering Programs

Each DDSN Operated Program or DSN Board/contracted service provider is required to develop and distribute a service recipient/family handbook or information packet, which includes:

- DDSN Operated Program, DSN Board/contracted service provider specific information (i.e., location, office hours, staff names, contact information).
- Facility/program (i.e., residence, day program, etc.) specific information.
- Information about various advocacy and family/service recipient organizations. These will include local organizations as well as the South Carolina Protection and Advocacy System, the State Ombudsman's Office, and SLED.
- A copy of this directive and any other policies, as requested, relevant to the roles and responsibilities of service recipients and their families.
- DSN Board/contracted service provider procedures to request reconsideration of decisions.
- DDSN's Appeal and Reconsideration Policy and Procedures.

All facility-based programs and services will also establish procedures for orientation of new service recipients and their families. This orientation will include:

- Introductions to the facility, staff, service/programs offered.
- Visits/tours of available programs/services.

### Visitation

Once an individual enters a program/service, and with the concurrence of adult service recipients, the parents/guardians/family representatives may visit at any reasonable time depending on the situation and services being provided. Prior notice is encouraged in the interest of the service recipient's privacy and in maintaining program schedules. Programs should establish guidelines to facilitate family visitation and opportunities should be made available for families to visit in private.

Family visitations may be restricted or limited when it is determined by court order or by the circle of support to be in the service recipient's best interest for safety and security reasons. Any restrictions must be reviewed at least annually by the Human Rights Committee. Restriction or limitation of family visits shall not be used as a form of discipline or behavior management.

### Service Recipient's Planning Meetings

With the concurrence of adult service recipients, the parents/guardians/family representatives are considered to be a member of the individual's circle of support and must be invited to participate in planning meetings if the individual chooses to have a meeting. Planning meetings will be scheduled per the service recipient's choice and so that family representatives can attend if the service recipient so desires/chooses. If family representatives are unable to attend, an opportunity for input will be given to them. With the concurrence of the adult service recipient, a copy of the completed Service Plan(s) will be sent to the parents/guardians/legal representatives and documented in service notes.

### Communications

Service providers will establish effective channels of communication in order to keep parents/families informed. With the concurrence of adult service recipients, procedures for informing parents/guardians/family representatives of the service recipient's activities, serious behavior problems, any significant changes in their medical condition or serious incidents that may require special services or interventions will be developed. Notification will also be given if the individual receiving services is involved in any unusual occurrence or critical incidents such as alleged incidents of abuse or neglect, or has a serious illness or accident.

With the concurrence of service recipients, the parents/guardians/family representatives shall have an opportunity to talk with staff directly involved in the delivery of services to the individual.

Parents/guardians/family representatives are encouraged to take an active part in the delivery of services and supports. This includes periodic review of progress on goals and objectives established in the individual's Service Plan(s).

### Informed Consent

In cases where a proposed activity or procedure will create significant risk or harm, have a potentially irreversible impact, or intrude physically, psychologically or socially on the individual receiving services, parents and legal guardians will be required to give informed consent on behalf of the service recipient whenever the service recipient is under 18 years of age or is incapable of providing consent.

If the service recipient is over 18 years of age, incapable of providing informed consent and there is no legally appointed guardian, then consent is sought according to DDSN Directive 535-07-PD: Obtaining Consent for Minors and Adults.

### Release of Records and Confidentiality

All personal information including information contained in an automated database, will be considered confidential and privileged as required under the Health Insurance Portability and Accountability Act (HIPAA) and, if applicable, the Family Educational Rights and Privacy Act

(FERPA). However, upon the written request of or through a signed release by the individual receiving services or legal guardian, records/information may be released to appropriate parties.

Additionally, records may be inspected and the service recipient, parent or legal guardian shall have the right to question the relevance and appropriateness of information in the record. Procedures shall be established for requesting a review of the inclusion of information in the record.

#### Service Recipient/Family Organizations

To enhance quality programs, services, and supports, each DDSN Operated Program and DSN Board/contracted service provider should establish a Service Recipient/family organization. These groups serve as a communication link and facilitate understanding between providers and people receiving services. They also play an important role in providing a supportive resource among families following the birth of and during adjustment to a family member with a disability. These organizations may become involved in advocacy issues affecting individuals with disabilities in a service area and in fund-raising events that assist local programs.

As another means to promote quality, DDSN Operated Programs and DSN Boards/contracted service providers should develop a consumer review panel to review services from a service recipient/family perspective. If developed, the panel should develop tools to assist or provide structure in their review of services and get approval from the DDSN Operated Program or the DSN board/contracted service providers for their use. It is also recommended that contracted service providers develop similar review panels as described above.

#### Human Rights Committee

Each DDSN Operated Program, DSN board and contracted service provider shall establish a Human Rights Committee in accordance with DDSN Directive 535-02-DD: Human Rights Committee. Representation on the Human Rights Committees will include parents/family representatives and people receiving services.

#### Service Recipient Grievance/Review Procedure

Each DSN Board/contracted service provider will develop written procedures for the service recipient or his/her representative to request a reconsideration of decisions when there is concern that the action taken is not in their best interest. These procedures will be consistent with DDSN Directive 535-11-PD: Appeal and Reconsideration Policy and Procedures.

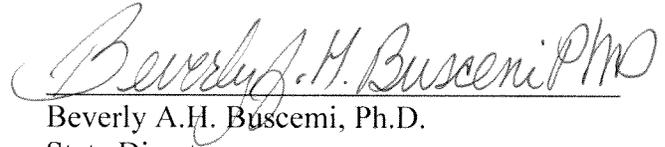
Behaviors related to an individual's disability or family complaints about a program are not sufficient reasons for a service provider to ask that a service recipient be removed from the program. Every effort shall be made to address behaviors and may include the development of a behavioral support plan. No one can be terminated from a program or service without consultation and concurrence of the Associate State Director for Policy and the Associate State Director for Operations.

Although the provider cannot, without consultation and concurrence by DDSN, remove a service recipient from a program, the service recipient may elect to receive services from another qualified provider at any time. Personal choice and the option to choose another qualified provider are fundamental rights for individuals receiving services through DDSN.



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