BALANCING THE RIGHTS OF CONSUMERS TO CHOOSE WITH THE RESPONSIBILITY OF AGENCIES TO PROTECT

GUIDELINES FOR RISK MANAGEMENT

SOUTH CAROLINA DEPARTMENT OF DISABILITIES AND SPECIAL NEEDS (DDSN)

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I. PURPOSE

The purpose of these Guidelines is to give service providers a decision-making framework within which balanced and defensible judgments may be made in distinguishing between reasonable and unreasonable risks in the lives of the people they serve.

NOTE: Decisions involving "proposed health care" are governed by the Adult Health Care Consent Act and DDSN Directive 535-07-PD: Obtaining Consent for Minors & Adults. For purposes of that policy, decisions involving healthcare are grouped into four categories:

1. Medical/diagnostic care, studies and procedures,
2. Psychotropic medication,
3. Restrictive programming/ behavior support plans, and
4. Admission/ placement/ discharge.

When decisions are being contemplated in these areas, those two documents take precedence over these Guidelines. However, once the substitute consent giver has been determined, concepts found in these Guidelines may be helpful to him/her in making the healthcare decision.

II. INTRODUCTION

An important component of the DDSN Risk Management Program is associated with balancing the goal of promoting consumer independence and self-determination with boards/providers responsibility to keep the individual safe from foreseeable harm. This area of risk management has taken on new importance over the last decade as a result of the shift in treatment/habilitation that has empowered consumers to be more in control of their lives and decisions.

Exposure to risk is a part of everyday life, and it is largely through making choices and assuming some risk that judgment (i.e., capacity) is developed. However, the ability to distinguish between reasonable and unreasonable risks is sometimes a complex task, and people with disabilities can be vulnerable to abuse, neglect, exploitation and a variety of other dangerous situations that may be the result of their own decision making.

III. PROCESS OF DETERMINING DEGREE OF RISK

Finding the balance between the boards/providers responsibility to protect people, while at the same time promoting their personal growth and autonomy, always begins with the individual and those who know him/her best. This would include the family, members of his/her "circle of support," and often the direct support professionals that work with the person on a regular basis.

A. PRESUMPTION OF FULL CAPACITY

In the eyes of the law, if a person is 18 years of age or older, and has not been adjudicated as incompetent, then there is a presumption that the person is competent to make his/her own life's decisions, and to assume the consequences of those decisions. (As mentioned above, this presumption may be restricted by the terms of the Adult Health Care Consent Act and DDSN Directive 535-07-PD: Obtaining Consent for Minors and Adults for decisions involving healthcare.)

B. FACTORS THAT REDUCE CAPACITY

There are certain factors that may be present in a person's life that reduce the validity of this presumption of competence. These factors generally exist with degrees of severity. Some of the factors that reduce the likelihood that a person is truly able to make all their own decisions and accept the risks involved include:

- Level of cognitive impairment
- Level of social adaptive impairment
- Level of expressive and receptive language impairment
- History and experience in decision making
- Presence of or degree of mental illness
- Presence of or degree of substance abuse

Using the above mitigating factors, a determination can be made as to whether the consumer has a reduced capacity to make their own decisions, and furthermore, the relative degree of the reduced capacity.

C. POTENTIAL FOR HARM

Not all decisions are of equal weight. Some decisions are of little consequence, while others may determine the quality and even the length of a person's life. The consequences of a decision, in relation to the amount of risk that is involved, may be determined by asking:

- What is the potential that harm will occur?
- What would be the severity of the harm?
- What would be the duration of the harm?

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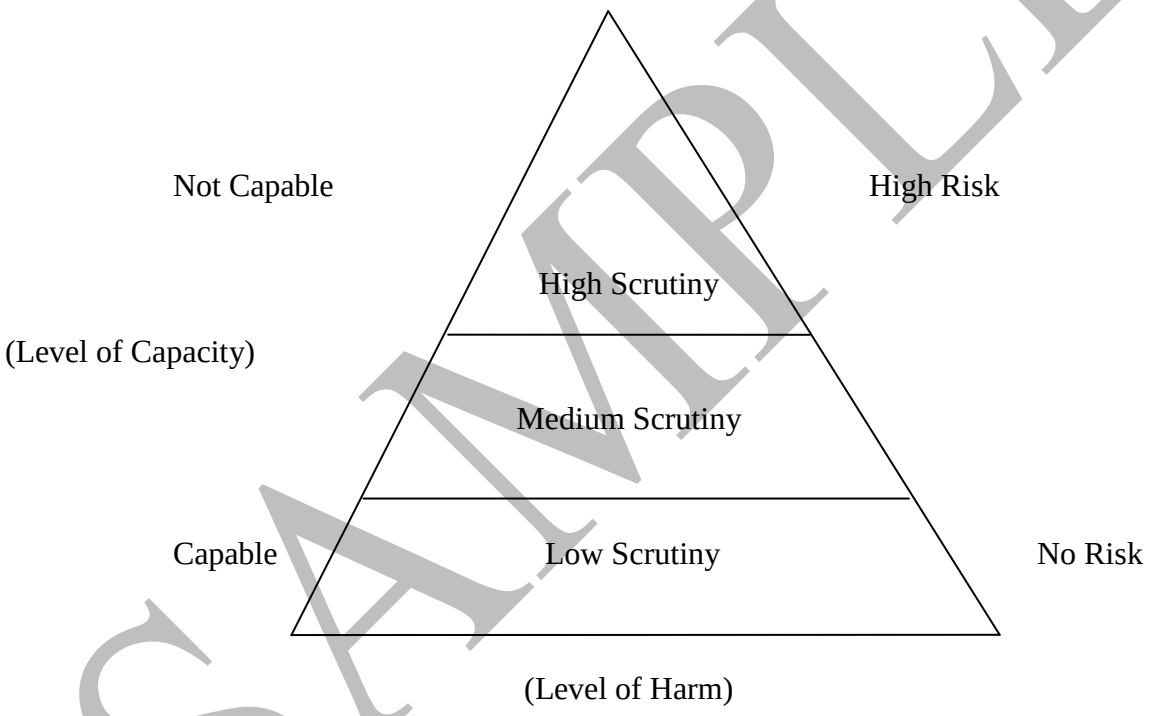
Using the above answers, a determination can be made as to the degree of potential harm associated with the decision, choice or situation under consideration. The more likely that harm will result from a decision or choice, the more competence the consumer should possess before that decision is left fully in their hands.

IV. LEVEL OF SCRUTINY TO BE APPLIED

Once the person's present level of competence is determined by reviewing the factors that reduce capacity, and the level of harm that may result associated with a particular decision or situation is determined, then a simple graph can be established that may guide how much scrutiny an agency, a team (or even a family) should give to various decisions/situations. Such scrutiny should involve a careful study or examination of a situation before moving forward. This is done by plotting the level of competence on the vertical axis and the amount of risk on the horizontal axis.



A. LOW SCRUTINY (low risk combined with high capacity) would indicate that the person can make these decisions by themselves.

B. MEDIUM SCRUTINY (medium risk and/or medium capacity) would indicate that the decision or situation requires support for the person, such as consultation with the family, circle of support, treatment team, etc. before the decision is made.

C. HIGH SCRUTINY (high risk and/or low capacity) would indicate that the decision should be made by the agency, or some other substitute decision maker, after consultation with the individual, family, team, professional staff, or employing other specialty consultations.

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The keys to establishing the proper balance between the individual's right to make his/her own decisions and boards/providers duty to protect from foreseeable harm or risk are in:

a) Having a rational basis for establishing any reduced capacity;
b) Having a rational basis for establishing any potential for harm; and then
c) Varying the degree of assistance/support given to the consumer based upon these first two factors

V. REDUCING RISKS TO THE CONSUMER

Just like the rest of us, good judgment can increase with training, experience, and consultation with others. The following strategies can be utilized in order to increase the consumer's capacity to make good decisions, and by so doing, reduce the risk of harm to the individual.

- Additional training
- Additional experience through practice or approximating
- Family support/ involvement
- Professional counseling
- Mentoring
- "Circle of Support" involvement
- Neighborhood support
- Staff supervision/shadowing/fading of supports
- Dividing a task/situation into those parts that may be done independently, and those parts where supervision/support is presently needed

VI. REDUCING RISKS TO THE AGENCY

Service and support providers need to assure that they are on firm ground from an ethical and a liability point of view, as they turn more and more control for decision making over to the consumer. If harm does occur to an individual under the boards/providers care and supervision, then the board/provider will need to document the steps that it took in order to properly balance the rights of a person to make their own decisions with the duty of the board/provider to protect from foreseeable harm. Below are listed some of the steps an agency can take to accomplish this.

- Utilize a rational, defensible process in assessing when a decision can be left in the hands of the consumer and when graduated supports should be applied.
- Seek family involvement in decisions.
- Use a team approach in deliberations.
- Seek outside consultations, a second opinion, or an "independent clinical review."
- Utilize the services of an ethicist or Ethics Committee when appropriate.
- Communicate with other boards/providers or DDSN's Central Office to determine what the standard of care has been in that particular area.
- Document deliberations and actions.
- Refer very difficult cases to the courts for adjudication.

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- Provide regular training to staff on making balanced decisions in this area.
- When in doubt, err on the side of health and safety.
- Assure that appropriate liability insurance is in place.

VII. ADDITIONAL RESOURCES AVAILABLE

Massey, P & Thompson, S; 1995, "Assisting People with Disabilities in Making Safe Decisions"; Distributed by AAMR, Washington, D.C.

Sundram, C.J., 1994. Choice and Responsibility: Legal and Ethical Dilemmas in Services for Persons with Mental Disabilities, New York State Commission of Quality of Care for the Mentally Disabled, Albany, NY.

Irwin Siegel Agency, Inc. "Great Expectations: Providing Choice- Minimizing Risk"

"Risk Management System"; Massachusetts Department of Mental Retardation, December 1998; Gerald Morrissey, Commissioner

"Code of Ethics", 2000, National Alliance of Direct Support Professionals; Institute on Community Integration, University of Minnesota

Allen, Shea & Associates, "Risks & Opportunities", excerpted from Patterns of Supported Living, A Resource Catalogue; Napa, CA, June 1993

"Obtaining Consent for Minors & Adults"; SCDDSN Policy Directive 535-07-PD

"Adult Health Care Consent Act" (AHCCA); S.C. Code Ann. Sec. 44-26-60 and 44-66-30 (Supp. 1999).

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