



MEMORANDUM

To: Erin Leveton, Legislative and Policy Analyst
State Office of Disability Administration, Department on Disability Services

From: Morgan K. Whitlatch, Senior Attorney
Quality Trust for Individuals with Disabilities

Re: Comments on Substitute Decision-Making Policy and Procedure

Date: October 1, 2013

Thank you for the opportunity to review and comment on the Department on Disability Services' (DDS) revised Substitute Decision-Making Policy and Procedure.

We appreciate DDS's leadership and interest in promoting less restrictive decision-making options through its practice, policies, and procedures. As you know, since its inception in 2001, Quality Trust has advocated, at both the systemic and individual levels, for people with intellectual and developmental disabilities (IDD) to be recognized and supported as active decision-makers and contributors to society. Decision-making is a learned skill, and people with IDD should be given an opportunity to take part in decision-making and build their capacity to do so throughout their lives. There are many ways to support people's decision-making without restricting, limiting, or removing their individual rights, and people's capacity to make decisions can change over time.

Both the draft Policy and Procedure take some important steps in the right direction. For example, unlike its predecessors,¹ the Policy expressly recognizes that the least restrictive decision-making option is the person making his or her own decisions, either independently or with support (see Policy § 6.F). The Procedure also now requires DDA to "ensure that people receiving services . . . are given the opportunity, support and information they need, to make decisions for which they have capacity" (see Procedure § 3.B.1). This approach is known as Supported Decision-Making, through which people with disabilities use their circles of support to help them understand the situations and choices they face and to help them in making informed and productive decisions. It is a critical issue for people with disabilities who need or want assistance making life choices and an alternative to overbroad or undue guardianship.

However, we believe that the draft Policy and Procedure need to go further in incorporating the principles of Supported Decision-Making throughout their provisions. As we note below, amendments are needed to clarify that a person with IDD does not automatically need a

¹ See DDS Substitute Decision-Making for Emergency Care and Urgent Care Medical Needs Policy (approved March 1, 2011) and DDS Substitute Decision-Making for Non-Emergency Needs Policy (approved March 1, 2011).

“substitute decision-maker” merely because they may need some “assistance in decision-making.” As DDS Definitions Appendix recognizes, a “substitute decision maker” makes decisions on behalf of another person.² By contrast, through Supported Decision-Making, people with disabilities continue to make their own decisions. It is only when a person cannot make certain decisions for him or herself – even when given appropriate support – that more restrictive decision-making options, like substitute or surrogate decision-makers, should be explored.

I. DDS DEFINITIONS APPENDIX

A definition of Supported Decision Making should be developed and incorporated in to the DDS Definitions Appendix. It is a concept that can be defined in both simple and more complex terms. In plain language, it involves a person making his or her own decisions by using friends, family members, professionals, and other people he or she trusts to help understand the issues, situations, and choices he or she faces, by asking questions and receiving explanations in language he or she understands. Or, in more legalistic terms:

Supported decision-making can be defined as a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist [a person] with a disability to make and communicate to others decisions about the [person’s] life . . . A purer form of supported decision-making would rely on peer support . . . , community support networks and personal assistance, so-called natural supports (family, friends), or representatives (pursuant to a representation agreement) to speak with, rather than for, the [person] with a disability.³

Supported Decision-Making is something all of us, regardless of whether or not we have a disability, use every day – *e.g.*, by contacting a lawyer to understand a complicated legal document, a doctor to understand an invasive medical decision, or a friend for advice on where to live or work. We cannot conclude that a person with IDD does not have the capacity to make any decisions at all, just because he or she needs some assistance in understanding the choices to be made or their potential ramifications.

II. POLICY

To recognize the full continuum of decision-making options available to a person, the title of the Policy should be changed to “Supported and Substitute Decision-Making Policy.”

A. Section 1 (Purpose)

For the reasons stated above, Section 1 should be amended to state:

The purpose of this policy is to establish the standards and guidelines by which the Department on Disability Services (“DDS”), Developmental Disabilities

² See DDS Definition of Substitute Decision Maker, *available at* <https://sites.google.com/a/dc.gov/dds-definitions-appendix> (last visited October 1, 2013).

³ See Robert D. Dinerstein, "Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making." Human Rights Brief 19, no. 2 (2012): 8-12, at p. 10, *available at* <http://digitalcommons.wcl.american.edu/cgi/viewcontent.cgi?article=1816&context=hrbrief> (last visited Oct. 1, 2013).

Administration (“DDA”), shall assist a person receiving its supports and services to make his or her own decisions, either independently or through Supported Decision-Making, or, if the person has been formally assessed to lack such capacity, to assist him or her with selecting or obtaining an appropriate and least restrictive substitute decision-maker. ~~for people receiving supports and services from DDA who have been assessed to lack the capacity to make or effectively communicate decisions for themselves.~~

B. Section 4 (Policy)

DDS’s policy should be “to ensure that all the people DDA supports who need assistance in decision-making obtain the most appropriate and least restrictive type of ~~substitute decision-maker~~ decision-making support in a timely manner, based upon the person’s assessed need.”

C. Section 6 (Standards)

New Subsection – The policy should expressly recognize that, in thinking about appropriate decision-making support options for a person, DDA must start by presuming the person is competent and has the capacity to make legal, health-care, and all other decisions for himself or herself. There are only two circumstances under D.C. law where we can depart from this presumption – *i.e.*, if the person is certified otherwise under the “two professional rule” of D.C. Code § 21-2204 or is deemed incapacitated or incompetent by a court.⁴ Incapacity cannot be inferred from the fact that a person has an intellectual disability or been determined by a court to be incompetent to refuse commitment by the Mental Habilitation Branch of the D.C. Superior Court.⁵

Subsection A (second sentence) should be amended to state: “If the person is assessed to need a substitute decision maker, that need shall be reviewed, at minimum, during his or her annual ISP meeting, and more often, upon the request of the person or any member of his or her support team.”

Subsection B should be amended to require DDA to “establish operating procedures for identifying a substitute decision-maker and/or obtaining a guardian for all people receiving services from DDA with an identified need that cannot be appropriately met through less restrictive alternatives, including Supported Decision-Making.”

Subsection C should be amended to require DDA to “assist the person with determining the least restrictive, but most appropriate ~~substitute~~ decision-making option to meet the person’s needs, based on a professional determination that a person lacks capacity or requires assistance to make decisions.”

Subsection D should be amended to require DDA “to expedite requests for the appointment of substitute healthcare decision-makers for people receiving supports and services who have been assessed to lack the capacity to make or effectively communicate medical decisions on their own behalf, even with support . . .”

Subsection D.1 and **D.2** distinguish between the need for “emergency” versus “urgent” treatment, setting forth different standards for addressing decision-making for those people who

⁴ See D.C. Code § 21-2002(d).

⁵ See D.C. Code § 21-2002(d)(2)

lack capacity to make their own decisions and do not have a substitute-decision maker available. The terms “emergency” and “urgent” need to be clearly defined and differentiated, which the DDS Definitional Appendix does not currently do.⁶ Without those kinds of definitions, it is difficult to assess the reasonableness of DDA’s self-imposed deadlines for filing a “temporary guardianship” petition – currently 3 business days for “emergency” circumstances and 10 business days for “urgent” care.

Subsection D.1 refers to the “two-professional rule” as being codified in D.C. Code § 21-2212(c), which it is not. Rather, D.C. Code § 21-2212(c) refers when an attending physician can provide emergency health care to a person without consent. D.C. Code § 21-2204 is the “two-professional rule,” a rule that can be applied not only to the provision of emergency health care under D.C. Code § 21-2212(c), but also to the selection of a substitute decision-maker under D.C. Code § 21-2210 of the D.C. Health-Care Decisions Act.

Subsection D states that, in both urgent and emergency circumstances, DDA “shall also consider whether to file concurrent petitions for a permanent limited or general guardian.” We believe this Policy should include express language requiring that, if the DDS Office of General Counsel (OGC) decides to file a permanent guardianship petition, the scope of the appointment sought must be limited to the greatest extent appropriate to meet the person’s needs and to recognize his or her abilities.

Subsection F should be amended to make it clear that less restrictive decision-making options are favored over more restrictive ones, provided that they can meet the needs of the person receiving DDA services and supports. For example:

The decision-making options (from least restrictive to most restrictive) to be considered, in order of priority, shall include . . . :

- a person making decisions independently,
- a person making decisions with support (also known as Supported Decision-Making)
- an advance health care directive,
- a durable power of attorney,
- a substitute health care decision-maker under D.C. Official Code § 21-2210,
- a representative payee,
- a court-appointed Developmental Disability lay advocate with medical decision-making authority,
- a court-appointed 21-day emergency guardian,
- a court-appointed 90-day healthcare guardian,
- a court-appointed permanent limited guardian, and
- a court-appointed general guardian.

⁶ See, e.g., DDS Definition of “Urgent Need” (“Significant risk of having basic human needs go unmet”) versus “Emergency” (“Any issue, whether individual or provider related, which requires or may require the immediate assistance or intervention of staff at DDA (i.e., serious behavioral, medical, imminent danger, issues which adversely affect individual care, movement of individuals due to fires, utility outages, flood staff shortages, and emergency”).

Subsection G should be amended to clarify that any documentation in the ISP and Health Passport about a person’s alleged incapacity to make medical decisions or to execute a durable power of attorney or an advance health-care directive must be based on a formal assessment by qualified professionals. Too often we have seen providers and family members calling into question people’s capacity, not based not on a formal capacity assessment that looks at the continuum of decision-making support needs, but because they disagree with a particular decision the person is making or do not fully appreciate the concept of dignity of risk.

Subsection H should be amended to expand DDA’s training program to a broader group of providers and their human rights committees, families, and – most importantly – the people with IDD who receive DDA services and supports. In Quality Trust’s experience, many families and health care providers are not aware of the full continuum of decision-making options available to people with disabilities under the DC law. This section also needs to recognize that substitute decision-making and guardianship are not the only answers for people with IDD who need support in making decisions. With these considerations in mind, we recommend this section state:

DDA shall maintain a training program for service coordinators, residential and day providers, providers’ human rights committees, people with intellectual and developmental disabilities and their families, and healthcare/medical services clinicians and providers to educate them on the current legal requirements and least restrictive options for supported and substitute decision-making, as well as the process and procedures for obtaining the timely appointment of a temporary or permanent guardian and the use of D.C. Official Code § 21-2212(c), which permits an attending physician to provide treatment in certain identified circumstances without consent if no authorized person is reasonably available.

III. PROCEDURE

To recognize the full continuum of decision-making options available to a person, the title of the Procedure should be changed to “Supported and Substitute Decision-Making Procedure.”

A. Section 1 (Purpose)

The purpose of this Procedure should be amended consistent with our recommendations for the corresponding section in the Policy (see our Part II.A of our comments above).

B. Section 3 (Procedures)

1. Section 3.A (“Determination of the Person’s Capacity”)

Subsection 1 should be amended to require that the psychological evaluation report specifically assess whether the person can make his or her own decisions either independently or through Supported Decision-Making. It also is important to recognize that a person may have the capacity to make some medical decisions (e.g., to have an annual physical) and not others (e.g., to have open heart surgery). Rather than being focused solely on a person’s IQ scores, the assessment needs to be based on a review of the person’s past experience with decision-making, to both acknowledge that the person may already have a history of making decisions with or without support, or may currently lack capacity because he or she has had no opportunity to learn how to make decisions and needs some practice in doing so. Suggested amendments to address these concerns are below:

“An appropriately constructed assessment will be completed by a licensed psychologist ~~and~~. It should be based on a review of the person’s past experience with decision-making, not solely IQ and other test scores. It should discuss in detail the person’s capacity in at least ~~six (6)~~ seven (7) areas of decision making, as well as the person’s ability to understand and execute a durable power of attorney and to make these kinds of decisions with and without support:

- a. Granting, refusing and/or withdrawing consent to non-invasive medical treatment,
- b. Granting, refusing and/or withdrawing consent to invasive medical treatment,
- c. Treatment other than medical (e.g., occupational therapy, behavioral supports)
- d. Habilitation, day programming and/or work,
- e. Type and place of residence,
- f. Finances, and
- g. Life planning

Subsection 2 should be amended to state that:

The assessment of capacity in each of ~~these six (6)~~ the above areas and the person’s need for support in decision-making should be considered when the person’s support team assists the person in determining whether the person ~~needs a~~ can make his or her own decisions, with or without support, and, if not, what kind of substitute decision-maker, and if so, is the least restrictive, appropriate option.”

Subsection 4 (second sentence) should state that a person’s support team should review the person’s changing needs in the area of decision making “at least annually as part of the ISP planning process, including, as needed or at the person’s request, requesting updates to the psychological assessment.”

Subsection 5.d should be amended to require the ISP to state whether the person “is incapacitated to make decisions, including a listing of the types of decisions the person is unable to make on his or her own behalf, even with support, and whether the person has or may need the assistance of an identified substitute decision-maker or court-appointed guardian.”

Subsection 5 (final sentence) should be amended to require the DDA Service Coordinator to base the ISP entry relating to a person’s capacity on formal psychological assessments – not only on their own opinions of the person’s capacity.

New Subsection – A section should be added to describe what a person’s rights are in the event he or she disagrees with DDA’s determination as to his or her capacity. This should include, for example, the right to an independent psychological evaluation, a referral to DDA’s Office of Rights and Advocacy and Human Rights Committee, and referrals to local legal service organizations that may be able to help.

Subsection 7 as written assumes that a person receiving DDA services will also need an identified substitute decision-maker or court-appointed guardian. The person’s support team

should instead consider “all options for supported and substitute decision-making in relation to the person’s needs and help the person choose the most appropriate, least restrictive form of assistance.” This section should also either cross-reference or specifically incorporate the priority list of decision-making options expressly contained in Section 3.F.6 of its Policy, as amended above (see Part II.C above).

Subsection 9 should be revised to clarify what professional is qualified to “deem” a person incapacitated to make health care decisions, “even with support.”

Subsection 9 also incorrectly cites the D.C. Code provision for the “two professional rule.” See comment to Policy Section 6.D.1 above. This error is also contained in other parts of the Procedure, including **Sections 3.D.3 and 3.F.2.**

2. Section 3.B (“Identification of Opportunities for Decision-Making”)

We appreciate that this Section recognizes DDA’s affirmative responsibility to ensure people receiving its services are given the opportunities and support needed to make their own decisions and to build their decision-making ability over time. This also should be an affirmative responsibility of DDA’s service providers, as decision-making is a learned skill that needs to be reinforced and practiced in a variety of settings. Thus **Section 1 and 2** should be amended as follows:

1. DDA and providers shall ensure that people receiving services from DDA are given the opportunity, support and information they need, to make decisions for which they have capacity.
2. DDA and providers shall provide people receiving services and supports form DDA opportunities to strengthen their ability to make decisions on their own behalf.

New Section – A section should be added to make clear that, even if a person has a guardian or a substitute decision-maker, the person should continue to be involved and consulted in the planning of their services, so that they have the opportunity to strengthen their decision-making capacity.

3. Section 3.C (“Identification of Possible Substitute Decision-Maker”)

Subsection 2 should be amended to state its procedures apply “[i]f the person lacks the capacity to make decisions on his/her own behalf, even with support, . . . ”

Subsection 2.b should be amended to state: “If the person is unable to identify someone to assist him or her or ~~cannot~~ does not have the capacity to execute a durable power of attorney by signature or mark, then the SC shall proceed with the process” of exploring possible substitute decision-makers and/or court-appointed guardians.

Under **Subsection 2.b.iii**, DDA Service Coordinators should be required to elicit and generally respect a person’s expressed preferences for who should serve as his or her substitute health care decision-maker under D.C. Code § 21-2210.

Subsection 2.b.iv allows for consideration of a host home provider as a potential substitute decision-maker for medical decisions on a case-by-case basis. We are concerned that this

allowance may not be consistent with the language and intent of D.C. Code § 21-2210(g), which prohibits “a health-care provider who is treating or providing services to the incapacitated patient at the time of the health-care decision” or “an owner, operator, administrator, or employee of, or a person with decision-making authority for, a health care provider treating or providing services to the incapacitated patient at the time of the health-care decision” from taking on that role. We believe this Procedure should make it clear who is prohibited by law from serving as a substitute health care decision-maker.

Section 2.b.v should be amended to recognize that, in order for a Service Coordinator to appropriately document the selection of a substituted health-care decision maker under D.C. Code § 21-2210, more is needed than merely asking the surrogate to sign a DDA form. D.C. Code § 21-2210 requires a written certification of mental incapacity to make health care decisions, pursuant the specifications of the D.C. Code § 21-2204’s “two professional rule.” We have seen cases where a substitute health-care decision-maker has been identified by the Service Coordinator without a clear record of this kind of legal certification.

4. Section 4.D (“Guardianship Application Tracking Procedures”)

Subsection 2.k raises concerns for us from a rights perspective. These procedures need to acknowledge that, when DDS files a guardianship petition in court, its interests may well diverge from the person’s own legal and expressed interests. The person may wish to contest the petition, the scope of the guardianship, or the selection of guardian. Discussions and decisions about whether the person wants to attend his or her guardianship hearing or wants to request a continuance should be between the person and his or her retained or court-appointed attorney – not by the Service Coordinator or DDS OGC.

Subsections 3 and 4 refer to two different protocols for handling “emergency” health care needs and “urgent” health care needs. More clarity on this distinction is needed, as noted in our comments on the accompanying Policy (see Part II.C above).

Section D.3 should be amended to state that: “If the person has been ~~deemed~~formally assessed to be unable to make medical decisions, even with support, and does not have any other type of lesser restrictive substitute decision-maker,” then the Service Coordinator and provider must take additional steps in emergency circumstances.

Section D.3 and D.4 should also incorporate use of DDA’s Issue System in the event the provider does not timely submit necessary information to DDA to support a temporary guardianship petition in “emergency” or “urgent” cases.

5. Section 4.E (“Post-Appointment or Post-Identification Issues with a Guardian or Substitute Decision-Maker”)

Subsection 1 currently states that guardians and substitute decision-makers are part of the person’s support network and that Service Coordinators and providers must keep them involved. Guardians and substitute-decision makers should be included if the person wants them to be or if the issues being discussed relate to their decision-making authority – which may be limited by law (e.g., to making health care decisions, if they are selected as substitute decision-makers under DC Code § 21-2210) or by court order (e.g., if they are limited or temporary medical guardians). Providers and Service Coordinators should have an affirmative obligation to be familiar with the scope and limits of a guardian’s or substitute-decision maker’s

authority and to act in a way that fully recognizes the continuing rights of the person to make certain decisions for him or herself.

Subsection 2 requires DDA Service Coordinators and providers to monitor any issues that arise with guardians or substitute decision-makers. The Service Coordinator must also document and follow up on such issues with his/her supervisor and the DDS OGC to determine if corrective action is needed. Additional issues to include in this subsection are situations when:

(g) the decisions being made by the guardian or substitute decision-maker appear to be beyond his or her authority under the law, court order, or power of attorney;

(h) the guardian ignores his or her duty to encourage the person to act on his or her own behalf whenever he or she is able to do so and to develop and/or regain capacity to make decisions to the maximum extent possible⁷;

(i) the person builds capacity to a point where the scope of the guardianship or substitute decision-making option becomes overly restrictive; and/or

(j) the person decides to revoke his or her power of attorney.

6. Section F (“Training”)

Consistent with our comments to Policy 6.H above, DDA’s training program described in **Section 1** should be expanded to a broader group of providers, their human rights committees, families, and people with IDD. DDA can partner with advocacy groups and organizations, including Quality Trust, to reach families, advocates, and people with disabilities.

Section 2 should be amended to state: “The training program shall include information on maximizing decision-making capacity for people with intellectual and developmental disabilities and the focus on least restriction options for decision-making, including Supported Decision-Making.”

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Thank you again for the opportunity to comment. We are happy to discuss any of our comments in greater detail. We look forward to the discussion at the Policy Review Group on October 9, 2013

⁷ See D.C. Code § 21-2047(a)(8).