



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

October 24, 2016

Ms. Tina Shockley, Education Associate
Department of Education
401 Federal Street, Suite 2
Dover, DE 19901

RE: 20 DE Reg. 233 [Proposed "Age of Majority" Regulation (Part 2) (10/1/16)]

Dear Ms. Shockley:

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Education's (DOE's) proposed regulation addressing educational decision-making upon a student's attainment of age 18. As background, the Disabilities Law Program (DLP), Governor's Advisory Council for Exceptional Citizens (GACEC) and other councils were highly involved with the drafting and enactment of State legislation (S.B. 180) implementing a federal regulation (34 C.F.R. 300) which addresses this issue. The legislation, enacted in June, requires the DOE to promulgate implementing regulations in consultation with the GACEC. Representatives of the DLP, GACEC, DOE, and school districts reached consensus on regulatory text in September. The DOE is now formally publishing two (2) sets of regulations based on that consensus. This is the second set of proposed regulations. The proposed regulation was published as 20 DE Reg. 233 in the October 1, 2016 issue of the Register of Regulations.

This regulation essentially "tracks" the requirements of S.B. 180 while adding some supplemental "common sense" provisions. For example, if the IEP team determined that a student lacked capacity in a prior review, the participation of a school psychologist in later IEP meetings would be "discretionary if it is clear there has been no change in the child's capacity." See §20.1.3.1.

Parenthetically, the DOE has incorporated some "housekeeping" revisions in the regulation unrelated to S.B. 180. For example, the DOE includes some minor edits to §11.0 to conform to changes in the relevant statute, 14 Del.C. §3137. The DOE is also amending §4.0 to require the provision of a copy of procedural safeguards to the parents at each IEP meeting. This conforms with a regulation adopted last month, 20 DE Reg. 172 (9/1/16).

SCPD is endorsing the proposed regulation subject to one important recommendation. At the federal level, the President's Committee for People with Intellectual Disabilities issued an October 6, 2016 report which includes "Recommendation 55" encouraging the sharing of information about supported

decision-making with families of IDEA transitioning students. See attachment. At the State level, the Governor signed S.B. 230 on September 15, 2016. That legislation authorizes competent adults to execute a “supported decision-making agreement”. It would be preferable for IEP teams to be aware of this option. For example, the new law specifically authorizes agents appointed through a supported decision-making agreement to assist with accessing educational records and assisting the principal (adult student) with educational decision-making. See, e.g. 16 Del.C. §§9403A(11)(h), 9406A(a)(2), and 9409A. Since the regulation (§20.1.2) already addresses powers of attorney and voluntary grants of authority, it makes sense to include a reference to supported decision-making in the same section. Consider adding the following bracketed second sentence to §20.1.2 as follows:

20.1.2. A child with a disability with capacity may authorize an adult agent to exercise rights through execution of a power of attorney or standard voluntary grant of authority form published by the Department of Education. [A child with a disability with capacity may also authorize an adult agent to provide assistance with making and communicating educational decisions through execution of a supported decision-making agreement authorized by 16 Del.C. Ch. 94A.]

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations and recommendation on the proposed regulation.

Sincerely,

Jamie Wolfe

Jamie Wolfe, Chairperson
State Council for Persons with Disabilities

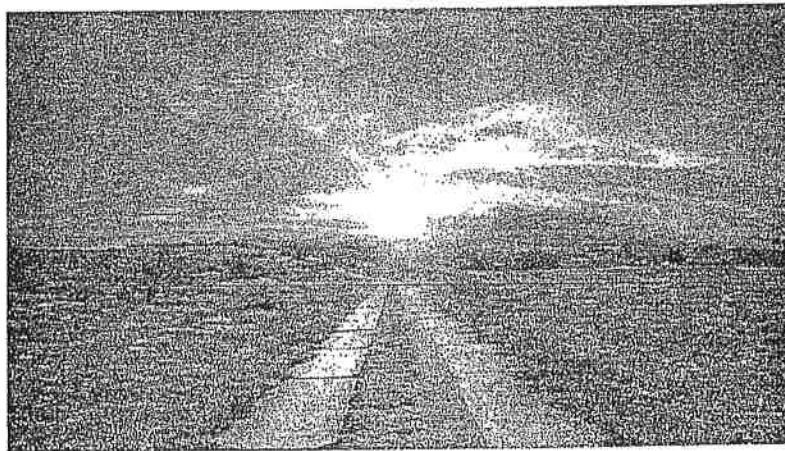
cc: The Honorable Nicole Poore
The Honorable Debra Heffernan
The Honorable Steven Godowsky, Ed.D, Secretary of Education
Mr. Chris Kenton, Professional Standards Board
Dr. Teri Quinn Gray, State Board of Education
Ms. Mary Ann Mieczkowski, Department of Education
Ms. Laura Makransky, Esq., Department of Justice
Ms. Terry Hickey, Esq., Department of Justice
Ms. Valerie Dunkle, Esq., Department of Justice
Mr. Brian Hartman, Esq.
Developmental Disabilities Council
Governor’s Advisory Council for Exceptional Citizens

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Report to the President

Strengthening an Inclusive Pathway for People with Intellectual Disabilities
and Their Families



2016

Supported decision-making is often defined as an individual using a team of trusted people (e.g., friends, family members, advocates) to help them understand a situation and the choices they have so they may make their own informed decisions to the best of their ability (Dinerstein, 2011–2012; Quality Trust, 2013). In a specific situation, supported decision-making takes into account the diversity of decisions to be made and can adjust the support a person needs depending on the nature of a given decision.

Although guardianship is still prevalent, supported decision-making is increasingly used as an augmentation to guardianship or even an alternative in the United States (Kohn, Blumenthal, & Campbell, 2013). The UN Convention on the Rights of Persons with Disabilities recognizes supported decision-making as a means to ensure access to human and civil rights for persons with disabilities, and several states have passed laws studying and authorizing the use of supported decision-making (Blank & Martinis, 2015). Supported decision-making can provide individuals with ID the skills to live self-determined lives and to enjoy the rights afforded them as humans and as citizens (Kohn et al, 2013).

Decision-making and self-determination involve both opportunity and teachable skills. Young adults who receive instruction to increase self-determination exhibit better employment outcomes, increased independence in daily-life activities, and more extensive community integration than those who do not (Powers et al., 2012; Shogren et al., in press). Studies have indicated a positive relationship between self-determination and quality of life. One such study found that young adults with greater self-determination were more likely to want to manage their own money, be employed in competitive integrated settings, and live independently (Wehmeyer & Schwartz, 1997). Other studies have found that adults who exerted more self-determination were more likely to live independently, protect themselves from abuse, and have higher-paying jobs (Wehmeyer & Palmer, 2003; Kehemka, Hickson, & Reynolds, 2005). Supported decision-making may increase self-determination and have a positive influence on an individual's quality of life.

Recommendations: Self-Determination and Supported Decision-Making

Recommendation #50: The U.S. Department of Health and Human Services (HHS-ACL) and the U.S. Department of Justice should monitor and study current guardianship laws in order to develop incentives for the adoption and expansion of augmentations and alternatives to guardianship, including supported decision-making.

Guardianship can be a problematic and a potentially abusive practice. More research must be conducted to determine the financial, political, and social incentives that maintain the system of guardianship. More research will also provide better data on the prevalence of guardianship and the monitoring that is or is not in place to protect people with guardians from abuse. In order for courts and providers to make informed decisions about guardianship and the use of alternatives such as supported decision-making, data regarding the use and outcomes of guardianship are necessary. As guardianship can severely limit an individual's civil rights, sound information is necessary for those in the position to determine whether a person is assigned a guardian. Research also should be conducted on the potential reduction or elimination of guardianship and the impact such a shift may have on those currently under guardianship.

Recommendation #51: The Administration for Community Living (ACL), in collaboration with the Administration on Children, Youth, and Families (ACYF), should support the development and continued use of systems for sharing information about supported decision-making and alternatives to guardianship for individuals with intellectual disabilities, as well as for those who are aging.

As new data and information emerge about best practices in supported decision-making, that information must become readily accessible and shared with families, courts, school personnel, and service providers. Organizations such as the National Resource Center for Supported Decision-Making (NRC-SDM) are leading and coordinating efforts to make supported decision-making a recognized alternative or augmentation to guardianship (Blank & Martinis, 2015). The NRC-SDM is acting as a clearinghouse for information on supported decision-

making, conducting research on best practices in supported decision-making, and establishing services, such as a website for families, self-advocates, and government officials, to share information and coordinate efforts in promoting supported decision-making. ACL should collaborate with NRC-SDM to ensure that information about supported decision-making is widely available.

Recommendation #52: The Office of Special Education and Rehabilitation Services (OSERS) and the Administration for Community Living (ACL) should jointly promote and distribute information about supported decision-making and self-determination as methods to engage individuals with intellectual disabilities in their own lives and exercise their rights throughout their lives.

The OSERS and the ACL should work jointly to disseminate information about self-determination skill development and supported decision-making for people with ID throughout their lives. This dissemination should frame decision-making and self-determination as basic human rights and as a natural part of the human experience. To improve the trajectory of inclusion for individuals with ID, they should be supported in developing such skills as early as possible. Professionals (e.g., teachers, child care providers, personal care attendants) should be knowledgeable about self-determination and supported decision-making skills and should provide opportunities for children and young people with ID to develop those skills.

Likewise, those in a position to make decisions about guardianship for people with ID should have access to information about alternatives. In a study exploring the awareness perception of guardianship and its alternatives among educators, students with disabilities, and parents, it was found that almost all parties were aware of the nature and process of guardianship but few were aware of any alternatives, such as supported decision-making (Millar, 2007). The ACL and the OSERS should put in place strategies to provide guardianship decision-makers, such as judges, court officials, social workers, and transition specialists, with information about alternatives to guardianship.

Recommendation #53: The U.S. Departments of Education, Labor, and Health and Human Services should include in their personnel development grant programs requirements for education about supported decision-making and guardianship.

For all competitive grants related to pre-service and professional development in each of the three departments, grantees should be required to provide evidence-based instruction about supported decision-making and its outcomes related to autonomy, self-determination, and quality of life. Likewise, instruction should be required about the potential abuses and negative outcomes associated with guardianship.

Recommendation #54: The U.S. Department of Justice should consider including a competitive preference for its Bureau of Justice Assistance competitive grant programs to expand the knowledge of court officers about supported decision-making and guardianship.

The Department of Justice, through its Bureau of Justice Assistance competitive grant programs, should offer a preference for applicants who include evidence-based instruction for judges and court officers about supported decision-making and its outcomes related to autonomy, self-determination, and quality of life. Likewise, instruction should be required about the potential abuses and negative outcomes associated with guardianship.

Recommendation #55: The U.S. Department of Education should require, as part of the requirements for reporting data for IDEA Indicator 13, that the notice provided to families and youth with disabilities leading up to the age of majority include robust information about the implications of guardianship and options for supported decision-making.

The U.S. Department of Education should include in its reporting requirements concerning transition activities the mandate for states and local school districts to supply data regarding the type of information they provide to families and youth with disabilities about shared decision-making and the implications of partial and full guardianship. The Department should use the most up-to-date information generated by the National Institute on Disability,



Independent Living, and Rehabilitation Research (NIDILRR), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and the National Institute on Aging (NIA) about supported decision-making. The Department should also provide guidance about the quality of information to be shared. The percentage of families and students with disabilities receiving such information should be reported annually.

The members of the President's Committee for People with Intellectual Disabilities are hopeful that this Report will provide a strategy for strengthening federal policies in the areas of: family engagement, education, transition, and self-determination and supported decision-making to place people with intellectual disabilities on a new trajectory to full inclusion and access to opportunities for the highest quality of life.