WRITTEN TESTIMONY OF
QUALITY TRUST FOR INDIVIDUALS WITH DISABILITIES, INC.

Before the Council of the District of Columbia, Committee on Education

PUBLIC HEARING:
Special Education Student Rights Act of 2014 (B20-723)
Enhanced Special Education Services Act of 2014 (B20-724)
Special Education Quality Improvement Act of 2014 (B20-725)

July 3, 2014

I. INTRODUCTION

Quality Trust for Individuals with Disabilities (Quality Trust) is an independent, non-profit advocacy organization that has been advancing the interests of people with intellectual and developmental disabilities (IDD) since 2001. We monitor the quality of services provided and advocate for whatever improvements are needed to enable people with IDD to live full, healthy, and meaningful lives. We have been addressing concerns about capacity and consent through education and training, individual advocacy, and legislative and policy reform for more than a decade. Over this time, we have worked closely with young and older adults with IDD, their families, their attorneys, D.C. governmental agencies, and others in their circle of support, so that people with IDD can build their skills for decision-making and make their own important life decisions to the maximum extent possible. To this end, in October 2013, we launched the Jenny Hatch Justice Project, an integrated, multi-faceted resource and outreach center dedicated to advancing people with disabilities’ right to make their own choices and determine their own path and direction in life. Quality Trust recognizes that the opportunity for self-direction is an essential part of dignity and respect for all people.

We – along with other education advocates who have testified before this Committee – welcome many of the proposed changes envisioned by this legislation, including reducing the age for starting school-to-adult transition planning to 14 years old, reducing the timeline for eligibility evaluations to 60 days, and giving parents the right to observe their children in class and designate others who may also observe their children. Rather than repeating that testimony of others, we will focus our comments today on two areas of the legislation that directly impact decision-making rights of adult students with disabilities in D.C. – one favorably, the other negatively:

• We are pleased that the legislation expressly recognizes powers of attorneys as available options for transition-age adult students with disabilities, given school and district agency personnel have resisted doing so.

• However, we are seriously concerned by the legislation’s proposal to authorize the D.C. Office of State Superintendent of Education (OSSE) to create a new extrajudicial alternative for involuntary appointment of an educational representative for adult students with disabilities. As we describe further below, there are strong legal and policy arguments against creating such a procedure, and we urge the Committee to reconsider including this mandate in otherwise welcomed legislation.

We have enclosed our recommended bill amendments as Attachment 1. We are happy to work with the Committee to discuss our concerns, as well as how to mitigate the negative impact if you should decide to pursue a new alternative appointment process over our objections.
II. EDUCATIONAL POWERS OF ATTORNEY, VOLUNTARY APPOINTMENT OF EDUCATIONAL REPRESENTATIVES, & SUPPORTED DECISION-MAKING

A. Background on “Transfer of Rights” Process in DC & Quality Trust’s Experience

By way of background, there is a “transfer of rights” process for adult students with disabilities in DC. While general education students typically graduate from high school by age 18, students in special education have the right to remain in school until the end of the semester in which they turn 22 years old. This means that there are a number of special education students in the District who are legally adults. Under D.C. law, when students turn 18, their parents’ rights under the Individuals with Disabilities Education Act (IDEA) automatically transfer to the student, unless a court has found that the adult student is incompetent.

In our experience working with transition-age students with IDD, we have seen a bias by schools and support teams to use the transfer-of-rights process to push parents towards going to court to get guardianship over their adult child, rather than first exploring less restrictive decision-making options, like powers of attorney and Supported Decision-Making. Pursuing guardianship should be a step of last resort – not the first – as it can remove people’s rights to make decisions over many aspects of their lives, like where to live or work, how to spend their money, and whether to vote or receive healthcare. Because of this institutional bias within disability service delivery systems, we have had to expend much effort and energy on counseling and supporting families to understand that guardianship may not be the only option.

B. Recognize the Validity of Educational Powers of Attorney

We strongly support the legislation including language that clarifies that adult students with disabilities have the right to delegate educational decisions through powers of attorney or similar legal documents. Quality Trust has long asserted that adult students with disabilities already have a clear civil right to execute educational powers of attorney under D.C. law. However, we have heard from parents that some schools are presenting the transfer of rights issue as a dichotomous choice between the students either exercising their educational rights without any support or their parents being required to go to court to have the students declared incompetent by court order.

As a result, beginning in September 2012, we co-led a coalition of stakeholders to ask OSSE, and then D.C. Public Schools (DCPS), to issue policy guidance recognizing existing decision-making support options other than guardianship, which can permanently take away students’ rights to make any decisions at all. While our advocacy efforts did result in DCPS formally recognizing one alternative to guardianship—Supported Decision-Making (discussed further in Part II.C below) – there continues to be a failure to fully recognize and inform parents and students of other alternatives, like the right for students to execute powers of attorney.

We therefore ask this Committee to take the additional step proposed in this legislation and, like other jurisdictions, reinforce the fact that adult students can indeed voluntary appoint an agent to exercise their special education rights.

C. Add Supported Decision-Making as an Option in Transfer-of-Rights Notices

We believe that this legislation also should include express requirements that transfer-of-rights notices to parents and students include of the full continuum of decision-making supports – not only powers of attorney, but also “Supported Decision-Making.” In plain language, Supported Decision-Making can be defined as:
Supports and services that help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts to help understand the issues and choices, ask questions, receive explanations in language he or she understands, and communicate his or her own decisions to others.\textsuperscript{14}

It 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. In order for Supported Decision-Making to get the same kind of traction or foothold that “guardianship” has gotten in the District’s public school system, including charter schools, it needs a clear name and definition that can be pointed to in transfer-of-rights notices, IEP meetings and school trainings. As we said, DCPS has taken that important step in its revised Transfer of Rights Guidelines, as have courts,\textsuperscript{15} legal literature,\textsuperscript{16} and advocacy discourse.\textsuperscript{17} We encourage the Committee to do the same, so that the District can remain in the forefront on this important civil rights issue for adults with disabilities.

### III. IMPROPER PROCESS FOR INVOLUNTARY APPOINTMENT OF EDUCATIONAL REPRESENTATIVE FOR ADULT STUDENTS

Quality Trust’s main concern about the legislation has to do with the new section 7(d)(a)(4) of Bill 20-0724, which requires OSSE to issue regulations “[e]stablishing a process to allow for the appointment of an educational representative to make educational decisions for an adult student with disabilities if that student has been determined to be unable to provide informed consent.” As we describe further below, we urge the Committee not to include this extrajudicial process for the involuntary appointment of an educational representative, given the strong legal and policy arguments against doing so. In the alternative, we do have recommendations for procedural safeguards to include to attempt to minimize the potential negative impact on adult students with disabilities – although we believe, even with these changes, the resulting process could open up the District to legal challenges.

#### A. D.C. Law on Capacity Does Not Authorize This Alternative Regulatory Process

First off, based on our discussions with OSSE and other advocates, we want the Council to be aware that IDEA does not require the District to establish the alternative process described in Bill 20-0724. While there is a “Special Rule” in IDEA on this topic,\textsuperscript{18} that rule only comes into play when a State’s law governing legal capacity allows for this extrajudicial process to be created.\textsuperscript{19}

The District’s governing statute on the topic of legal capacity – namely, D.C. Code Title 21, Chapter 20 (Guardianship, Protective Proceedings, and Durable Powers of Attorney) – does not authorize a regulatory process that would allow for the involuntary appointment of an educational representative for an adult, absent a court order. Under District law, a person age 18 or older is “presumed competent and to have the capacity to make legal, health-care, and all other decisions for himself or herself” unless one of two things happens: (1) a court finds the person incapacitated in a guardianship proceeding; or (2) the person falls under a narrow exception created for only health care decisions under the D.C Health Care Decisions Act.\textsuperscript{20} This law makes no exception for educational decisions.

Therefore, creating this kind of exception can neither be delegated to OSSE through regulation – as Section 7(d)(a)(4) of Bill 20-0724 purports to do – nor can it be accomplished solely through amendment of the State Education Office Establishment Act of 2000, D.C. Code § 38-2601 \textit{et seq}. It also would arguably require detailed review and hearings by other Committees of the D.C. Council, including the Committee on the Judiciary. In addition, it could unintentionally, but unlawfully,
discriminate against adult students with disabilities under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, as they – unlike other adults in the District – could lose their rights to make decisions for themselves, without a formal court process to protect them.

B. Probable Overuse Will Unduly Infringe on the Decision-Making Rights of Adult Students with Disabilities

Given that District educational agencies and schools have not fully embraced the rights of students to voluntarily appoint their own educational representatives, we also are concerned that the kind of alternative process described in Bill 20-0724 will become the default for adult students with IDD – many of whom can exercise choice for themselves when appropriately included and supported in decision-making. Since legal capacity is a continuum, even those that cannot provide informed consent for complicated educational decisions may still be able to choose a person they trust to make those decisions for them through a voluntary appointment of an educational representative. We are concerned that, with this alternative process, schools and IEP teams will not fully explore and exhaust other less restrictive decision-making alternatives that support self-determination and build young adults’ capacity.

Our concerns are justified. Our practical experience with the kind of information schools in the District are sharing with parents who contact us suggests a strong and troubling bias away from the presumption of capacity and towards the use of surrogate decision-making strategies, where decisions are made for adults with IDD, rather than by them. Based on District statistics released within the last year, we are concerned that the D.C. Health Care Decisions Act – an already existing extrajudicial mechanism for providing surrogate informed consent for health care – is being overused for people with IDD. According to D.C. Department on Disability Services’ statistics, over 70% of adults with IDD served have either a guardian (over 29%) or substitute decision-maker (over 41%), less than 19% make their own decisions with or without support, and less than 0.14% use a durable power of attorney. This raises questions as to whether support teams are effectively exploring less restrictive decision-making options before resorting to surrogate decision-making or guardianship.

Therefore, we urge the Committee to focus its attention on promoting existing alternatives to guardianship that support young adults’ self-determination, instead of creating an easier way for it to be taken from them that may well violate District and federal law.

C. In the Alternative, the Negative Impact Must be Actively and Legislatively Mitigated

While we have serious legal and policy concerns, we realize and appreciate that much of the effort that led to proposing the alternative transfer-of-rights process described in Bill 20-0724 is borne from the commendable desire to help adult students and families avoid overly expansive or burdensome guardianships. If the Committee decides to go forward with the establishment of that process, we do have recommendations to offer to minimize any negative impact – although we remain concerned regarding the legal and policy ramifications. These recommendations include:

- The D.C. Council must go further in giving OSSE specific guidance on the content of the applicable regulations, so that the full continuum of decision-making supports are recognized, least restrictive alternatives favored, and the rights of the student to challenge maximized.

- When a student with a disability reaches the age of eighteen, there must be a presumption that all rights accorded to the parents under Part B of IDEA automatically transfer to the adult student.
• The transfer-of-rights procedural safeguards must recognize the full continuum of decision-making support, including (in order of preference) Supported Decision-Making, powers of attorney, any new alternative process of involuntary appointment, and – as the last resort – adult guardianship. Less restrictive alternatives must be fully explored and exhausted before more restrictive ones are pursued.

• Any written certification that an adult student does not have the capacity to make educational decisions, with or without support, or to voluntarily appoint an agent to exercise those rights, must be strictly limited to special education decisions and valid for only those purposes. Neither the written certification nor the results of OSSE’s extrajudicial regulatory process should be able to be considered evidence, precedential in any way, or relevant to any future court or legal action seeking to remove decision-making authority from the person.

• Any such written certification must be immediately void and legally inapplicable if the adult student objects to it in any way at any time. In other words, if the adult student challenges the certification, all rights under IDEA Part B would automatically transfer to the student, and the extrajudicial involuntary appointment option would not be available.

Thank you very much for your attention to these important matters. Your work does and will mean a great deal to the thousands of D.C. residents with IDD and their families that Quality Trust supports. If you have any questions or wish to discuss these issues further, please do not hesitate to call me at 202-459-4004 or MWhitlatch@DCQualityTrust.Org.

Respectfully submitted by:

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2 See Enhanced Special Education Services Act, B 20-0724, Washington D.C. Council Period 20, Sec. 102(b) (2014) (creating a new Section 7d(a)(1)).
3 See id. at Sec. 202(b) (2014).
5 D.C. Mun. Regs. tit. 5, § E3002(b).
7 See Special Education Student Rights Act, B 20-0723, Washington D.C. Council Period 20, Sec. 3(6) (2014) (“An adult student shall be allowed to designate, in writing, by power of attorney or similar legal document, another competent adult to be the student’s agent to receive notices and participate in meetings and all other procedures related to the student’s educational program”).
8 See D.C. Code §§ 21-2101 et seq. (D.C. General Power of Attorney statute); see also 71 Fed. Reg. 46,450, 46,713 (Aug. 14, 2006) (U.S. Dept. of Education comments on 34 C.F.R. § 300.520(b), which recognize the role powers of attorney can play when a student with a disability reaches the age of majority under the Individual with Disabilities Education Act).
(finding that guardianship is “the most severe form of civil deprivation which can be imposed on a citizen of the United States,” and that the typical Ward has fewer rights than a convicted felon).


13 See, e.g., Ariz. Rev. Stat. Ann. § 15-773(B) (stating that a student who has reached the age of majority “may execute a delegation of right to make educational decisions pursuant to this section for the purpose of appointing the pupil’s parent or agent to represent the educational interests of the pupil”); 14-926 Del. Code Regs. § 19.5 (states that adult student generally have “the right of access to a surrogate parent; the right to refuse the appointment of a surrogate parent; the right to participate in the selection of a surrogate parent; and the right to terminate the services of a surrogate parent”); Haw. Code R. § 301a-491(b) (states that an “adult student may execute a power of attorney for special education”); 105 Ill. Comp. Stat. 5/14-6.10 (stating that the adult student has the right to “execute[] a Delegation of Rights to make educational decisions . . . for the purpose of appointing the student’s parent or other adult to represent the educational interests of the student”); 603 Mass. Code Regs. 28.07(c) (states that the adult student “may choose to delegate continued decision-making to his or her parent, or other willing adult” and that “[s]uch choice shall be made in the presence of at least one representative of the school district and one other witness and shall be documented in written form and maintained in the student record”); N.H. Code Admin. R. Ed. 1120.01(c) (states that “an adult student may authorize an individual to act on their behalf pursuant to a duly executed power of attorney”); N.M. Code R. 6.31.2(K)(1) (stating that an adult student generally has a right to “sign[] a power of attorney as provided under New Mexico law”); Or. Admin. R. 581-015-2325 (states that a “child to whom rights transfer may request that a surrogate be appointed to exercise the child’s special education rights”); 19 Tex. Admin. Code § 89.1049(e) (states that “[n]othing in this section prohibits a valid power of attorney from being executed by an individual who holds rights under IDEA, Part B”); 8 Va. Admin. Code 20-81-180(C)(2) (stating that the “adult student [can] designate[] in writing, by power of attorney or similar legal document, another competent adult to be the student’s agent to receive notices and participate in meetings and all other procedures related to the student’s educational program”); Wash. Admin. Code § 392-172A-05135(6) (states that “[n]othing within this section shall prevent a student, who has reached the age of majority, from authorizing another adult to make educational decisions on that student’s behalf using a power of attorney” under state law).

14 See, e.g., Robert D. Dinerstein, Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: Disabilities, The Difficult Road from Guardianship to Supported Decision-Making, 19 Hum. Rts. Brief 8, 10 (Winter 2012), http://digitalcommons.wcl.american.edu/cgi/viewcontent.cgi?article=1816&context=hrbrief (last visited July 1, 2014); Texas H. B. 1454 (2009) (Tex. Code Ann. 531.02446(a)(4), now expired) (“‘Supported decision-making services’ means services provided for the purpose of supporting a person with intellectual and developmental disabilities or a person with other cognitive disabilities who lives in the community to enable the person to make life decisions such as where the person wants to live, who the person wants to live with, and where the person wants to work, without impeding the self-determination of the person.”); Virginia House Joint Resolution No. 190 (2014) (“[S]upported decision-making is a process through which individuals with intellectual and developmental disabilities receive assistance in making and communicating important life decisions.”)


16 See Dinerstein, supra note 2 at 10.

18 See 30 U.S.C. § 1415(m)(2); see also 34 C.F.R. § 300.520(b) ("A State must establish procedures for appointing the parent of a child with a disability, or, if the parent is not available, another appropriate individual to represent the educational interests of the child through the period of the child’s eligibility under Part B of the Act if, under State law, a child who has reached the age of majority, but has not been determined to be incompetent, can be determined not to have the ability to provide informed consent with respect to the child’s educational program") (emphasis added).

19 See 71 Fed. Reg. 46,450, 46,713 (Aug. 14, 2006) (U.S. Dept. of Education comments on 34 C.F.R. § 300.520(b)) ("Section 300.520(b) recognizes that some States have mechanisms to determine that a child with a disability who has reached the age of majority under State law does not have the ability to provide informed consent with respect to his or her educational program, even though the child has not been determined incompetent under State law. In such states, the State must establish procedures for appointing the parent . . . to represent the educational interests of the child throughout the remainder of the child’s eligibility under Part B of the Act") (emphasis added).


21 See id.

22 See DDS, Annual Plan of the Department on Disability Services to the Council of the District of Columbia on Substitute Decision Makers and Psychotropic Medication for People with Developmental Disabilities (For Fiscal Year 2014), at 3 (November 1, 2013) (on file with the author).
Attachment 1

Recommendations for Additions to Transfer-of-Rights Language in Special Education Reform Legislation

Special Education Student Rights Act of 2014 (B20-723)

Sec. 2 Definitions

[In addition to other definitions . . . ]

(9) “Supported Decision-Making” means supports and services that help an adult child make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts to help understand the issues and choices, ask questions, receive explanations in language he or she understands, and communicate his or her own decisions to others.

Sec. 3 Procedural safeguards; due process requirements.

[In addition to other procedural safeguards…]

(6) When a child with a disability reaches the age of eighteen, all rights accorded to parents under Part B of IDEA transfer automatically to the adult child, including adult children who are incarcerated in an adult or juvenile, state, or local educational institution, unless:

(A) The adult child chooses to share or delegate educational decision-making with his or her parent, or another competent adult.

(i) The adult child’s choice shall be documented in writing by the IEP team or through a validly executed power of attorney.

(ii) The adult child’s choice shall prevail at any time that a disagreement occurs between the adult child and the parent or other adult with whom the student has shared or delegated decision-making.

(iii) The adult child may revoke, in writing, their choice to share or delegate educational decision-making at any time.

(B) Upon parent request, two professionals, based on personal examination of the child with a disability, certify in writing that the adult child both does not have the capacity to make educational decisions, with or without support, and does not have the capacity to share or delegate decision-making with his or her parent or another competent adult.

(i) The professionals cannot be related to the child with a disability and cannot be employed by the LEA serving the child.

Comment [MW1]: As stated in our 7/3/2014 comments, Quality Trust continues to have serious legal and policy concerns with the inclusion of this kind of certification process. If the Committee decides to go forward with establishing it over our objections, we do have recommendations to offer to minimize any negative impact (see below).
(ii) The professionals shall be licensed to practice in the District and qualified to make a determination of mental capacity. Both certifying professionals shall give an opinion regarding the cause and nature of the mental incapacity to make educational decisions, as well as its extent and probable duration.

(ii) One professional must be a physician, physician’s assistant whose certification is countersigned by a supervising physician, or a certified nurse practitioner, and the other professional must be a licensed clinical psychologist, a psychiatrist, or a licensed clinical social worker.

(iii) The adult child must be informed, verbally and in writing, of the certification and his or her right to challenge the certification. In the event an adult child challenges the certification in any way and at any time, all rights under Part B of IDEA automatically transfer to the adult child, the certification is void, and [Section 3(6)(B)] is legally inapplicable to the adult child.

(iv) An adult child may be certified as lacking capacity to make educational decisions only if, when provided appropriate assistive technology and information at an age and ability-appropriate level, the adult child is unable to, even with Supported Decision-Making:

(a) Understand the nature, extent, and probable consequences of a proposed educational decision;

(b) Make an evaluation of the benefits or disadvantages of a proposed educational decision;

(c) Communicate an educational decision in any meaningful way; and

(d) Voluntary choose to share or delegate educational decision-making with his or her parent or another competent adult.

(v) An adult child shall be presumed capable of making educational decisions unless certified otherwise under [Section3(6)(B)]. Mental incapacity to make an educational decision or voluntarily choose to share or delegate educational decision-making shall not be inferred from the fact that the adult child:

(a) Has been voluntarily or involuntarily hospitalized for mental illness pursuant to § 21-501 et seq.;

(b) Has a diagnosis of intellectual disability or has been determined by a court to be incompetent to refuse commitment under § 7-1301.01 et seq.; or

(c) Has a conservator or limited guardian appointed pursuant to § 21-2001 et seq.
(vi) Certification of incapacity under this section shall be strictly and solely limited in its effect to the capacity to make educational decisions or to voluntarily choose to share or delegate educational decision-making in the special education context. It shall not be construed as a finding of incompetency or incapacity for any other purpose, or as relevant or precedential evidence in any future court or legal action seeking to remove decision-making authority from the adult child.

(C) The adult child has been found legally incapacitated by the District of Columbia Superior Court or another court of competent jurisdiction and a legal guardian has been appointed by the court to make decisions, including educational decisions, for the student.

(7) The local education agency shall notify the parents(s) and the adult child of the transfer-of-rights provisions described in [Section 3(6)]. The notice shall include a description of the full continuum of decision-making options available to the child when the child turns eighteen, including (from least restrictive to most restrictive) independent decision-making, Supported Decision-Making, voluntary sharing and delegation of educational rights and powers of attorney, the certification process described in [Section 3(6)(C)], and, as a last resort, legal guardianship. The IEP team shall assist the adult child in exploring the least restrictive decision-making option appropriate to meet his or her needs and express wishes.

Enhanced Special Education Services Act of 2014 (B20-724)

Sec. 102. The State Education Office Establishment Act of 2000…

(b) A new section 7d is added to read as follows:

“Sec. 7d. Special Education.

“(a) By October 1, 2015, OSSE shall issue regulations:

“(4) Establishing a process where rights accorded to parents under Part B of the IDEA do not transfer to a child with a disability who reaches the age of eighteen and has been certified as lacking capacity to both make educational decisions, with or without support, and share or delegate educational decision-making, consistent with the requirements of the Special Education Student Rights Act of 2014.