

# PLANNING WITH SPECIAL NEEDS YOUTH UPON REACHING MAJORITY: EDUCATION AND OTHER POWERS OF ATTORNEY

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## I. INTRODUCTION.

A logical extension of special needs trust work on behalf of families with a disabled child or other relative is planning for disabled young adults. Together with health care and financial powers of attorney, this article proposes using an education power of attorney as an appropriate, but simple, planning tool for an adult, mentally competent, disabled child, who acknowledges the need for his or her parents’ continuing stewardship over educational matters.

The seeds of this article were sown in 1995, when Nancy, the parent of Matt, a young man with autism, approached Attorney Hughes with a request to represent her son after he reached eighteen, the age of majority in Wisconsin. Although Matt was severely affected by his autism, he was “gifted and talented” in mathematics and other areas, and generally high functioning. Nancy believed he had sufficient capacity to execute health care and financial powers of attorney, but also believed that it would

benefit Matt if she remained involved in his education planning because he was eligible for special education services until age twenty-two.

During discussions with Nancy, it became apparent that Matt could benefit from a limited power of attorney. While Matt would often function well, his autism did limit him. For example, he did not function well when faced with the pressure of registration lines and choices. Another trait was difficulty with communication. His concrete thinking, typical of persons with autism, meant that he had difficulty understanding the meaning and function of ordinary documents, such as release forms for education information. He could neither understand nor navigate the complexities of the various education and employment support resources available to assist disabled young adults in moving toward their personal education and employment goals.

Necessity became the mother of invention. Matt's mother saw a need and asked Hughes to invent a solution. The result was an education power of attorney. Through this experience, attorney, parent and child all learned that a well-drafted power of attorney can extend the important parental role of advocating for appropriate educational services for a disabled child without unduly restricting independence and self-sufficiency, which is the goal of special education.

Hopefully, sharing this education power of attorney and the process of its development will assist other attorneys who provide services to competent, special needs youth and their families. While the "case study" here was a young man facing the challenges of high-functioning autism, his issues parallel those of young persons with other disorders.

## II. PARENTAL ROLE IN THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT.

Because special education law sets the stage for any discussion of educational rights, this article begins with an examination of the Individuals with Disabilities Education Act, 20 U.S.C. §1401 *et seq.* (IDEA),<sup>1</sup> which entitles every disabled child to the opportunity for "special education"—"specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability...."<sup>2</sup> In amending this law in 1997 and again in 2004, Congress found that "Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities."<sup>3</sup>

Noting that "low expectations" and an "insufficient focus" on research based "methods of teaching and learning" have "impeded" implementation of special education laws,<sup>4</sup> in 1997 Congress also strengthened the role of parents in ensuring

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1. All IDEA citations in this article are to the Individuals with Disabilities Education Act as amended by Pub. L. 105-197, 111 Stat. 37, June 4, 1997, and as amended by the Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-446, signed by President George W. Bush on December 3, 2004. Amendments to IDEA that are pertinent to this article will take effect on July 1, 2005. Pub. L. No. 108-446, Title III § 302.

2. 20 U.S.C. § 1402 (25) (1997); as of July 1, 2005, 20 U.S.C. § 1402(29).

3. 20 U.S.C. § 1401(c)(1) (1997) and (2005).

4. 20 U.S.C. § 1401(c)(4) (1997).

implementation of the Act.<sup>5</sup> Parents have extensive rights, including the rights to participate in planning evaluations of their child, to arrange private evaluations of their child, to vigorously participate with the school district in educational planning for their child, to receive written notices and explanations of actions taken by the school district with respect to their child, and, if they disagree with the school district, to request a “due process” hearing to review their child’s educational program.<sup>6</sup>

At present, parental advocacy, ultimately through “due process” and ensuing judicial review, is the primary enforcement mechanism of IDEA.<sup>7</sup> Neither the Justice Department nor the United States Department of Education enforces individual entitlements under IDEA. And though state departments of education do have complaint procedures that may address individual complaints, the state’s ultimate sanction, cutting off federal special education funding to a school district, is too draconian a remedy to be useful in individual cases. State agencies may obtain voluntary compliance, but if they do not, it is left to parents to file due process to enforce favorable complaint resolutions.

Implicitly recognizing that children with special needs may require extra time to learn “to be prepared to lead productive, independent, adult lives, to the maximum extent possible,”<sup>8</sup> special education eligibility begins with pre-school at age three and extends until the child is twenty-two.<sup>9</sup> Despite this extended eligibility period, IDEA allows states to transfer all parental educational rights to the child at the age of majority.<sup>10</sup> In states where the age of majority is eighteen, this means that the child is put in the “driver’s seat” before completion of the education that is intended to teach him or her how to “drive.” Up until the age of majority, it is the parent’s decision whether to include the child in IEP team meetings,<sup>11</sup> but after the child reaches the age of majority, the parent attends at the discretion of the child or the school district.<sup>12</sup>

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5. 20 U.S.C. § 1401(c)(5)(B) (1997).

6. *See generally*, 20 U.S.C. §§ 1414-15 (1997) and (2005).

7. *See e.g.*, *Weast v. Schaffer*, 377 F.3d 449 (4th Cir. 2004). The Individuals with Disabilities Education Improvement Act of 2004 may enhance the federal and, by extension, the state enforcement roles by specifying how the U. S. Department of Education must monitor and enforce overall state compliance. Pub. L. 108-446, § 101, inserting a new § 616 into IDEA as of July 1, 2005. Where federal intervention is required, referral to the U. S. Department of Justice is one enforcement remedy available to the U. S. Secretary of Education. §616(e). Whatever the efficacy of these new remedies, they address systemic issues. Hence the new scheme is unlikely to supplant the parental role in obtaining a free appropriate public education (FAPE) for their individual children.

8. 20 U.S.C. § 1401(c)(5)(E)(ii) (1997); as of July 1, 2005, 20 U.S.C. § 1401(c)(5)(A)(ii).

9. 20 U.S.C. § 1412(a)(1) (1997) and (2005).

10. 20 U.S.C. § 1415(m)(1) (1997) and (2005).

11. 34 C.F.R. § 300.344(a)(6); Notice of Interpretation of IDEA regulations, 34 C.F.R. Part 300, Appendix A, Answer to Question 6 (1999).

12. *Id.*

### III. SUMMARY OF IDEA RIGHTS AND PROCEDURES.

IDEA guarantees each disabled child a free appropriate public education, or “FAPE.”<sup>13</sup> FAPE is developed and delivered through procedures prescribed in IDEA that guarantee the right of parental participation and are intended to insure the delivery of a substantively appropriate individualized education. The Supreme Court has instructed that whenever a child’s educational program is challenged, the court must perform a two-pronged analysis. First, the court must inquire whether the school district has complied with the procedures set forth in IDEA. Second, the court must inquire whether the individualized educational program developed through the Act’s procedures is “reasonably calculated to enable the child to receive educational benefits.”<sup>14</sup> Despite this two-pronged analysis, procedural compliance is so important under IDEA that a serious procedural error by the school district, of itself, can constitute a denial of FAPE.<sup>15</sup>

IDEA’s procedural requirements are complex. School districts are obligated to identify children potentially in need of services<sup>16</sup> and to evaluate them in all areas of suspected disability to determine eligibility.<sup>17</sup> The child’s parent is entitled to participate both in the planning meeting for the evaluation and in a follow-up meeting that discusses the results of the evaluation and determines eligibility.<sup>18</sup> For eligible children, within 30 days of completing the evaluation,<sup>19</sup> the school district must develop and offer an Individualized Education Program, or “IEP,”<sup>20</sup> drafted by the “IEP Team,” a group that includes the child’s parents, teachers, administrators, therapists, and others with specialized knowledge of the child.<sup>21</sup>

The IEP must conform to detailed statutory and regulatory requirements.<sup>22</sup> Among other things, it must include:

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13. 20 U.S.C. § 1402(8) (1997); as of July 1, 2005, 20 U.S.C. § 1402(9).

14. *Bd. of Ed. of Hendrick Hudson Central Schl. Dist. v. Rowley*, 458 U.S. 176, 206-07 (1982).

15. Courts have held that procedural non-compliance denies FAPE when it causes “substantive harm” to parent or child. Instances of substantive harm include: 1) depriving the student of an Individual Education Program; 2) seriously infringing upon the parent’s opportunity to participate in the IEP process; or 3) causing the student to lose educational opportunity. *Knable v. Bexley City School District*, 238 F.3d 755, 763 (6th Cir. 2001). Similar provisions are included in the Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-466, § 101 inserting new § 615(f)(3)(E)(ii) into IDEA.

16. 20 U.S.C. § 1412(a)(3)(A) and (B) (1997) and (2005).

17. 20 U.S.C. § 1414(a) and (b) (1997) and (2005).

18. 20 U.S.C. § 1414(c)(1)-(4) (1997) and (2005); 34 C.F.R. § 300.533 (1999).

19. 34 C.F.R. § 300.343(b)(2) (1999).

20. 20 U.S.C. §§ 1401(11) and 1414(d) (1997); as of July 1, 2005, §§ 1401(15) and 1414(d).

21. 20 U.S.C. § 1414(d)(1)(B) (1997) and (2005). A school district’s failure to convene a properly constituted IEP team meeting is an example of a procedural error that has been held to deny FAPE. See e.g., *Arlington Central School District v. D.K. and K. K.*, 2002 U.S. Dist. LEXIS 21849 at 16-17 (S.D.N.Y. 2002).

22. 20 U.S.C. § 1414(d)(1)(A) (1997); as of July 1, 2005, 20 U.S.C. § 1414(d)(1)(A)(i)(II); 30 C.F.R. § 300.347 (1999).

- a child's "present levels of performance," which is a description of how the child's disability affects involvement in the school district's general curriculum;
- annual goals for the child;
- a description of the special education, related services, and supplementary services to be provided, together with the anticipated frequency, location and duration of those services;
- an explanation of the extent of appropriate mainstreaming, i.e, integration with typically developing peers;
- a description of appropriate and necessary modifications in state or district-wide achievement tests; and
- an explanation of how the child's progress in meeting goals will be measured.

By age fourteen (or, under the 2004 amendments to IDEA, no later than the first IEP to be in effect when the child is sixteen),<sup>23</sup> the IEP team must begin planning for delivering "transition services" to the child: a "coordinated set of activities," based upon the child's individualized needs, that facilitates "movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation..."<sup>24</sup>

Parents are entitled to participate as equals in IEP team meetings.<sup>25</sup> If the parent makes requests that the school district refuses, or if the parent otherwise expresses disagreement, the school district must provide "prior written notice" to the parent, explaining its reasons for acting or refusing to act and identifying options considered.<sup>26</sup> Parents who are dissatisfied with the IEP can request a due process hearing seeking specific additional services from the school district.<sup>27</sup> Alternatively, if the parents believe the IEP does not offer FAPE, pursuant to notice requirements,<sup>28</sup> they may unilaterally place their child in an appropriate, private placement, and file due process seeking tuition reimbursement.<sup>29</sup>

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23. Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-446, § 101, inserting new § 614(d)(1)(A)(i)(VIII) into IDEA. Current provisions, which will expire when the new law takes effect, are at 20 U.S.C. § 1414(d)(1)(A)(vii) (1997).

24. Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-446, § 101, inserting § 602(34) into IDEA. This new language makes only slight changes in current law at 20 U.S.C. § 1402(30) (1997).

25. 34 C.F.R. § 300.344(a)(6); Notice of Interpretation of IDEA regulations, 34 C.F.R. Part 300, Appendix A, Answer to Question 9 (1999).

26. *Id.*; see also 20 U.S.C. § 1415 (b)(3) and (c) (1997) and (2005).

27. 20 U.S.C. § 1415(f) (1997) and (2005).

28. 20 U.S.C. § 1412(a)(10)(A) (1997); as of July 1, 2005, 20 U.S.C. § 1412(a)(10)(c).

29. *Florence County School District IV v. Shannon Carter*, 510 U.S. 7 (1993); *School Committee of the Town of Burlington v. Department of Education*, 471 U.S. 359 (1985).

A myriad of other statutes and regulations govern disciplinary procedures,<sup>30</sup> requirements for placement in the least restrictive environment,<sup>31</sup> the right of an independent educational evaluation at school district expense,<sup>32</sup> and other important matters.

#### IV. IDEA'S TRANSFER OF RIGHTS PROVISIONS.

IDEA allows the states to transfer responsibility for navigating this complex, regulatory environment to the disabled child when he reaches the age of majority under state law.<sup>33</sup> Though couched in permissive language, "A State... *may* provide that, when a child with a disability [who has not been determined incompetent] reaches the age of majority under State law... all other rights accorded to parents under this part transfer to the child,"<sup>34</sup> the popular assumption about IDEA is that there *must* be a transfer of rights to the child at the age of majority.<sup>35 36</sup>

The recognition that competent adults are entitled to enjoy the right of self-determination underlies IDEA's transfer of rights provision.<sup>37</sup> After all, the goal of IDEA is independence and self-sufficiency. Still, IDEA allows states to create procedures to ensure continuing parental participation for a child who has not been determined to be incompetent, "but who is determined not to have the ability to provide informed consent with respect to the educational program of the child."<sup>38</sup> Where such a possibility exists, "the State shall establish procedures for appointing the parent of the child," or another individual "if the parent is not available."<sup>39</sup>

Legislative history does not reveal what Congress intended in this provision. Federal Register comments regarding IDEA's implementing regulations seem to imply something akin to a limited guardianship proceeding, where "competence" is considered only with respect to certain matters.<sup>40</sup> However, it is unlikely that Congress intended to limit the options for extending parental involvement to guardianship proceedings. Even limited guardianship usually requires a judicial determination of incompetence,<sup>41</sup> and it is a cumbersome procedure that could be

30. 20 U.S.C. § 1415(k) (1997) and (2005); 34 C.F.R. §§ 300.519-529 (1999).

31. 20 U.S.C. § 1412 (a)(5) (1997) and (2005); 34 C.F.R. §§ 300.550-577 (2004).

32. 20 U.S.C. § 1415 (b)(1) (1997) and (2005); 34 C.F.R. § 300.502 (1999).

33. 20 U.S.C. §§ 1415(m) (1997) and (2005).

34. 20 U.S.C. § 1415(m)(1)(B) (1997) and (2005).

35. Some states, such as Colorado, appear to recognize a sharing of parental rights, as opposed to displacement of the parent by the child. *Division of Youth Corrections*, 103 LRP 27305 (Colorado SEA, January 13, 2001).

36. IDEA's regulations provide that "In a State that transfers rights at the age [of] majority," one year prior to transfer, at age 17 for states where 18 marks legal adulthood, the school must inform the child of his or her rights that will transfer within a year. 34 C.F.R. § 300.347(c) (1999).

37. *Rogers v. Commissioner of Department of Mental Health*, 390 Mass. 489, 458 N.E.2d 308 (1983), cited in *Dudley-Charlton Public Schools*, 28 IDELR 588, 28 LRP 5067 (MA SEA, June 24, 1998).

38. 20 U.S.C. § 1415(m)(2) (1997) and (2005).

39. *Id.*

40. 64 Fed. Reg. 12405 (March 12, 1999).

41. See e.g., Ohio Rev. Code § 2111.02 (2004).

counterproductive for a child whose goal is to learn to lead a “productive, independent adult” life “to the maximum extent possible.”<sup>42</sup>

In contrast, the appropriate use of a power of attorney is far more consistent with the purposes of the Act. Every state permits the use of powers of attorney. Powers of attorney preserve the young adult’s right of self-determination by allowing him or her to elect whether to request assistance.

## V. POWERS OF ATTORNEY

Powers of attorney have their origins in the common law of agency: a competent adult may designate and authorize another adult to act on his behalf.<sup>43</sup> While under common law a power of attorney ends if the principal becomes incapacitated, today all states have durable power of attorney statutes that permit the principal to provide that transfer of rights survives his or her subsequent incompetence.<sup>44</sup>

A durable power of attorney is an inexpensive and convenient alternative to guardianship. Though not originally designed to deal with “personal care decisions,” commentators have argued in favor of using them for such decisions.<sup>45</sup> Indeed, before states enacted statutes expressly providing for health care durable powers of attorney, commentators promoted both use of common law and general durable power of attorney statutes to effect the delegation of health care decisions.<sup>46</sup> Courts permitted the practice.<sup>47</sup>

Powers of attorney are limited by the “non-delegable acts doctrine,” the notion that some decisions are too personal to be delegated,<sup>48</sup> but that doctrine should not stand as an impediment to an educational power of attorney.<sup>49</sup> There is growing

42. See generally, 20 U.S.C. § 1401(c)(5)(E)(iii) (1997); as of July 1, 2005, 20 U.S.C. § 1401(c)(5)(A)(ii).

43. Joyce E. McConnell, *Securing the Care of Children in Diverse Families: Building on Trends in Guardianship Reform*, 10 Yale J.L. and Feminism 29 at 42-43 (1998).

44. Edward J. O’Brien, *Refusing Life-Sustaining Treatment: Can We Just Say No?*, 67 Notre Dame L. Rev. 677, 694 (1992).

45. See *supra* n. 145 (citing Mark Fowler, *Appointing An Agent to Make Medical Treatment Choices*, 84 Colum. L. Rev. 985 (1984)).

46. Mark Fowler, *Appointing An Agent to Make Medical Treatment Choices*, 84 Colum. L. Rev. 985, 1012-1020 (1984).

47. *Cruzan, by her Parents and Co-Guardians, Cruzan et ux. v. Director, Missouri Department of Health et al.*, 497 U.S. 261, 290-292 (1990) (O’Connor, J., concurring).

48. See *supra* n.46, at 1015. See also, Restatement (Second) Of Agency § 17 (1957) (stating that a person privileged or subject to a duty to perform an act or accomplish a result can properly appoint an agent to perform the act or accomplish the result, unless public policy or the agreement with another requires personal performance; if personal performance is required, the doing of the act by another on his behalf does not constitute performance by him).

49. As noted above, despite this doctrine, nearly all states permit competent adults to delegate the most personal decision of all—the right to consent to or refuse medical treatment that may affect whether the principal continues to be alive—through a health care durable power of attorney. Educational decisions are not as personal because they do not carry the same possibility of irreversible consequences as health care decisions and do not usually implicate life and death. In education, there is almost always an opportunity to change your mind and correct mistakes. If health care

judicial and statutory acknowledgement that educational rights are not too personal to be delegated. States have allowed parents to delegate their right to make educational (and other) decisions regarding their minor children through powers of attorney, albeit for limited periods of time. In *Feaster and Carpenter v. Portage Public Schools*,<sup>50</sup> the Michigan Supreme Court upheld a power of attorney delegating parental rights and ruled that such a delegation was adequate to require the child's enrollment in the agent's school district even though the parent resided elsewhere. Courts in Illinois<sup>51</sup> and Texas<sup>52</sup> have issued similar decisions, and other states have enacted statutes<sup>53</sup> that permit a parent to delegate parental rights through a power of attorney of six months' duration.

Other current legal authority reflects acceptance of educational powers of attorney. In *In re: Westport Board of Education*, a simple consent from a student who had reached the age of majority was deemed sufficient to authorize his parent to prosecute due process on his behalf.<sup>54</sup> *Say the Right Thing*, a weekly on line publication of LRP Publications designed to help administrators, principals and staff prepare for parental requests at IEP team meetings, advises school districts to routinely ask the child if he wishes to grant educational rights to his or her parents rather than exercising them himself.<sup>55</sup>

If a parent can delegate educational rights regarding a minor child, there is no reason to deny the competent child the same ability to delegate educational rights when he or she reaches the age of majority. Such delegations need not be time limited, because the considerations that motivated legislators to limit parental delegations to six months are not present when the student delegates his or her own educational rights. Powers of attorney terminate upon the death of a principal. If the parents of a minor child die in such a situation, the agent loses authority to act on behalf of the child. Setting six month duration on a parental delegation means that some part of the adult world will likely be reviewing the child's status every six months, providing the opportunity to consider whether appropriate protections for the minor are in place.

In contrast to the minor child, a child who has reached the age of majority is presumed able to make his own decisions, and enjoys that legal right. Death of a parent, of itself, will not mean that the individual has no one to act on his behalf. Since the adult child is the principal, death of the parent does not destroy his ability to

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decisions are not too personal to be delegated, then certainly educational decisions are not too personal either. Since the child's parent—the very person who has been making educational decisions on behalf of the child all along—is the most likely agent under an educational power of attorney, the delegation should present no new issues or difficulties.

50. *Feaster v. Portage Public Schools*, 547 N.W.2d 328 (Mich. 1996).

51. *Israel S. by his aunt, Deborah W. Owens v. Board of Education of Oak Park and River Forest High School*, 601 N.E.2d 1264 (Ill. App. 1st Dist. 1992).

52. *Billie Carl Major, et al. v. Nederland Independent School District*, 772 F. Supp. 944 (E. D. Texas, 1991).

53. See R.S. Mo. § 475.024 (2004); N.M. Stat. Ann. § 45-5-104 (1978, Repl. Pamp. 1989).

54. 102 LRP 20168 (SEA CT, October 17, 2001).

55. See generally, *Say the Right Thing: Transfer of parent rights at age of majority*; Individuals with Disabilities Education Law Reporter; Special Education Connection (July 23, 2003).



delegate or obtain help elsewhere. Hence, the periodic review prompted by a six month durational limit is less necessary than where a minor is involved.

The one reported challenge to an educational power of attorney was not successful. In *In re: Beachwood City School District*,<sup>56</sup> the adult child, who had not been declared incompetent, had executed a durable power of attorney that included a delegation of educational rights. A petition seeking due process was filed on behalf of both the parent and child. The school district moved to dismiss on the grounds that, because the child had reached the age of majority, the durable power of attorney was invalid to transfer educational decision-making authority back to the parents.

The hearing officer upheld the durable power of attorney and refused to dismiss the case for several reasons. First, the child testified that he wanted his parents to help him make decisions regarding his education. Second, the school district cited no persuasive legal authority supporting its argument that educational rights could not be delegated. Third, state law which recognized limited guardianship<sup>57</sup> authorized courts to deny even limited guardianship where less restrictive alternatives exist.<sup>58</sup> Case law recognized that a power of attorney is a less restrictive alternative than guardianship.<sup>59</sup> Since a power of attorney is a viable option for a partially competent individual in lieu of limited guardianship, by extension, it is also appropriate for an individual who has never been adjudged even partially incompetent and who presumably is fully capable of delegating authority. Finally, the hearing officer noted that the child continued to reside with his parents and was dependent upon them for financial support.

The hearing officer found no evidence that the state had finalized or disseminated procedures ensuring continued parental participation for children who needed help but had not been determined to be incompetent, as envisioned by 20 U.S.C. §1415(m)(2). She decided not to hold the lack of a written policy against the parent and child and instead recognized the validity of the durable power of attorney, correctly reasoning that continued parental support was consistent with IDEA's intent that handicapped children enjoy a free and appropriate public education.<sup>60</sup>

## VI. POWERS OF ATTORNEY AND AUTISM

Estate planners should take note of the recent upsurge in children and young adults diagnosed with autism and the related disorder, Asperger's Syndrome.<sup>61</sup> Even

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56. 104 LRP 25307 (Ohio Dept. of Educ., March 11, 2004).

57. Ohio Rev. Code § 2111.02(B)(1) (2004).

58. *Id.* at § 2111.02(C)(6).

59. *Guardianship of Standel*, LEXIS 4979 (Ohio 9th App. Dist. 1995).

60. On appeal, the State Level Review Officer found that the IHO's findings and conclusions regarding the durable power of attorney were unnecessary because the student was one of the parties who had requested the appeal. *In re: Beachwood City School District*, 104 LRP 30663 (SEA Ohio, June 17, 2004).

61. Dawn Prince-Hughes, *Understanding College Students With Autism*, 49(17) *The Chronicle of Higher Education* B16 (January 3, 2003). Ms. Prince-Hughes is an adjunct professor of anthropology at Western Washington University. This article was excerpted from *The Chronicle of Higher Education* from *Aquamarine Blue 5: Personal Stories of College Students With Autism*

without significant impairment of mental capacity, young adults with autism or Asperger's Syndrome, whether in high school or college, can often benefit from an education and other durable powers of attorney.

*A. Selected Characteristics and Challenges of Young Adults with Autism or Asperger's Syndrome.*

In her article entitled "Understanding College Students with Autism,"<sup>62</sup> Professor Dawn Prince-Hughes describes a variety of autistic behaviors, some of which can be mistaken for inattention, boredom, drug abuse, rebelliousness or even mental illness. Such behaviors include: vigorous rocking; tic behaviors such as grimacing or coughing; twirling movements; repetitions of the same question to the teacher; difficulty with written output; unusual fixation about a particular area of interest; disregard of personal appearance and hygiene; impulsive or uncensored speech; rigid or ritualistic behaviors; sensory issues such as extreme sensitivity to light, noise, odors, food textures, or clothing textures; difficulty transitioning between classes or events; problems in recognizing faces and in distinguishing professor from classmates; self-absorption; insatiable curiosity; and lack of awareness of social norms and unwritten rules.

As Prince-Hughes describes, the internal needs and motivations of autistic students are often at odds with the physical environment and the social and emotional demands of college. High school and vocational school may pose similar challenges. Unfortunately, because of their behaviors, these promising students with special needs may be rejected or ignored by other students and are frequently overwhelmed by the new sights and sounds, changes and confusion of the educational institution. Despite their intellect and unique insights, too often autistic or Asperger's students leave the educational settings that can maximize their potential, with a concomitant societal loss of their gifts.

*B. Planning Strategy to Make Life More Manageable.*

Most young adults with autism or Asperger's will not be able to fend entirely for themselves in school settings, whether secondary or post-secondary institutions. For those with autism, life can be very hard work. As the mother of Hughes's client with autism explained, society is full of unwritten rules. Persons with autism do not automatically understand the rules. Consequently, they struggle to adapt and feel comfortable. When these students, who are already burdened with an underlying disability, further experience the life stresses that come with demands and expectations of secondary and post-secondary education, they may have "meltdowns" because they may have no energy left to cope with a new challenge. This is where the education

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(Swallow Press/Ohio University Press, 2002), which she edited. According to Prince-Hughes, a potentially significant number of college students fall on the autism spectrum without being identified as such. Ideally, such students would have been identified in high school, through the special education procedures under IDEA.

62. *Id.*

power of attorney can be extremely valuable as it provides someone, the agent, to assist the disabled student through the educational obstacle course.

Interruption or loss of educational progress and career preparation will have life-long negative consequences for the individual with high functioning autism or Asperger's. Most of these individuals have the potential to be not only self-supporting but also contributing members of society. Some are highly creative, showing ingenuity that enables them to solve problems in ways that "neuro-typical" individuals cannot quite see. The loss of their ability to contribute their talents is a societal as well as an individual loss.

By granting powers of attorney for education, health care, and financial matters to a trusted family member or other appropriate individual, the autistic young adult can enlist assistance for the new challenges, making them manageable rather than catalysts for meltdowns.

## VII. CREATING THE EDUCATIONAL POWER OF ATTORNEY

There are two alternatives for instruments delegating powers to carry out education-related acts. First, these acts can be included in a general durable power of attorney instrument delegating other acts, such as those involving management of financial matters, hiring of professionals, initiation and settlement of litigation, filing of tax returns, and the like. Inclusion of education-related powers in a general durable power of attorney instrument would be analogous to the inclusion of health care powers in similarly broad instruments as was necessary before the advent of statutory health care power of attorney instruments.

The second, and preferred, alternative is to delegate appropriate acts in a specific education power of attorney instrument. This alternative is more effective because it provides third parties with a focused instrument addressing only the kinds of acts that concern them. A power of attorney targeted to educational matters also avoids confusing school officials with a "kitchen sink" document and prevents unnecessary disclosure to school officials of possibly confidential information pertaining to financial planning on behalf of the young adult.

In response to her initial client request, Attorney Hughes devised a stand-alone instrument. She worked from her previous public school teaching experience to devise a "Special Durable Power of Attorney for Matters Concerning Education," the most recent version of which appears at the end of this article. The instrument incorporates a series of powers that are either necessary or useful to the agent, who in most cases will be the parent(s). In an approach that other attorneys may find effective, Hughes drafted an instrument including several numbered, but blank paragraphs, and then contacted the school district's attorney, requesting not only that he review the proposed document but also that he add other useful powers. In particular, she asked him to add appropriate language incorporating exercise of rights under the Individuals with Disabilities Education Act, as well as the appropriate reasonable accommodations

in education language incorporating Section 504 of the Rehabilitation Act of 1973.<sup>63</sup> In this way, the school district's attorney became engaged in and familiar with the creation of the instrument that Hughes sought to have the school district accept. His additions to the power of attorney gave him a "stake" in its acceptance and success.

The need for cooperation between school district and parents cannot be emphasized enough. Delicacy is advised. As the child approaches the age of majority, competing and sometimes conflicting interests arise between school, parent, and child. The school district may welcome the transfer of rights to the child at the age of majority because the school can then advise the child directly, without parental intervention. A parent, accustomed to advocating for his child since the age of three, may not be happy to relinquish that role and may believe, with justification, that the child does not yet have the skills for effective self-advocacy. The child, for his or her part, may have a mixed agenda. Teens are rebellious, and disabled teens may be especially frustrated by school due to years of struggling with reading, math, social skills, friendships, or behavior. Empowering eighteen-year-olds before they are ready to exercise authority in their own best interests allows them to set their parents against the school, sometimes with questionable educational results.

The sample instrument is drafted broadly and is not limited to the child's period of eligibility for special education services under IDEA, which ends at the earlier of graduation or age twenty-two. While this was the period of initial concern, as Matt moved on with his education and enrolled in post-secondary school settings, the POA remained valid and proved to be useful. It was accepted and used at the vocational/technical school and college levels, where bureaucratic requirements continue to be a daunting task at times even for the agent.

### VIII. PRACTICAL CONSIDERATIONS

Moderate to high functioning persons with autism or Asperger's who wish to authorize their parents to continue to make decisions or have an ongoing involvement with their education, health care or financial affairs will need to meet with an attorney. The threshold duty of that attorney is to ascertain whether the individual has the capacity to enter into an attorney-client relationship.

When initially approached with the request for powers of attorney for Matt, Hughes first clarified that he, not his mother, would be the client, provided that he was able to enter into an attorney-client relationship with her. Her conferences with Matt were somewhat unusual because of his disorder. As is typical with many autistic individuals, he did not make eye contact, and their conversation was more stilted than with neurotypical clients. Nonetheless, it was very clear to Hughes that Matt wanted to enter into the relationship with her; that he grasped the purpose of the separate powers of attorney for education, health care, and financial matters; that he sufficiently

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63. Section 504 of the Rehabilitation Act of 1973, (P.L. 93-112) is an anti-discrimination law that requires recipients of federal funds, including school districts, to make appropriate accommodations on behalf of disabled individuals so that they can enjoy equality of access to education.

understood the documents that she had drafted for him; and that he wanted his mother to continue in her past role as advocate and assistant.

Where, as with Matt, the client has a somewhat diminished capacity, Rule 1.14 of the Model Rules of Professional Conduct instructs the attorney to maintain a normal client-lawyer relationship with the client to the extent possible. It should go without saying that it is imperative to treat these young, disabled clients with dignity. The attorney must accept them as they are, modulating responses to their unusual behaviors and using simple language to explain complex, but understandable ideas.

Over the past decade, in meeting with a variety of young clients with autism or Asperger's, Hughes has learned from both the parents and the clients themselves that the attorney must be very organized and alert in conferences. Small talk and subtlety can interfere with the client grasping the points being made by the attorney. Parents of the client can help in advance by aiding the attorney to recognize areas of sensitivity and behavioral cues that indicate whether the client understands what is being discussed. The attorney must be alert to when the client either needs a break from or an end to the conference. Patience is not the strong suit of eighteen-year-olds in general, and is even less so for young adults with autism.<sup>64</sup>

Parents can help prepare their children prior to the initial conference by explaining to them that having this meeting with the lawyer is part of growing up. Parents also can explain in advance that the powers of attorney being contemplated do not take any power away from the young person, but merely enable the parents to continue participating in decision making and in assisting and advocating for their now "adult" child. In every such planning conference, the attorney needs to reinforce this concept.

## IX. CONCLUSION

Along with financial and health care powers of attorney, attorneys should consider the education power of attorney for any disabled child turning eighteen and in need of continuing guidance or advocacy from his or her parents. For a child who is competent, a power of attorney is an inexpensive instrument that is likely to be accepted by courts, hearing officers, and most school districts. Attorneys should note that the child should not execute the power of attorney before he or she turns eighteen because the delegation will not be valid if signed before the age of majority.

For a child who is not competent, however, a power of attorney is not a viable option. Because the principal must be competent to execute a power of attorney, a document executed by an individual who lacks competency is void. For a borderline competent child, a power of attorney is problematic. If the agent appointed under the power dies or becomes incapacitated, the power of attorney terminates, with the result that the less than competent child may be left without an individual to take action on his or her behalf or even notice that help is needed. Because there is no automatic,

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64. Many young people, disabled or not, also have an aversion to discussing certain aspects of health care powers of attorney, in particular their wishes for care in the face of a life-threatening illness or persistent vegetative state.

periodic court supervision or review of powers of attorney as in the case of guardianship, the disabled child may be left adrift, lacking necessary supervision, assistance or advice. When planning for disabled children, attorneys must give careful consideration to all their needs, particularly their ability to fend for themselves in the event the caretaker adult becomes incapacitated or dies. In certain circumstances, to properly protect the child, the wisest course may be to proceed directly to guardianship in order to provide a court-supervised surrogate decision maker.

Appropriate use of an education power of attorney can have a profound impact upon the young adult's educational progress and life trajectory. Matt's experience exemplifies what is possible. This young man is a very gifted mathematician who completed University of Wisconsin mathematics courses while still in secondary school. Graduating from the Madison Area Technical College (MATC) with an associate degree, he transferred to the University of Wisconsin. Thanks to the power of attorney, not only was he able to have his mother's assistance and involvement during his adult years in secondary school, but because both MATC and the University of Wisconsin accepted the education power of attorney and allowed his mother to assist him, he was able to deal with the kinds of activities that would normally have led him to a meltdown. The education power of attorney helped Matt and his mother to thread their way through the stressful, bureaucratic aspects of paying his tuition and fees, registering for courses, and coordinating among his education support staff, vocational support staff, and the Division of Vocational Rehabilitation counselors.

At age twenty-six, Matt is now able to live alone in an apartment, manage his daily finances, and is on track to graduate from the University of Wisconsin. Thanks to his work experience, his giftedness in mathematics, and his greatly improved social and speaking skills he has developed with the committed assistance of his mother, his teachers and others, he faces a future bright with potential. He will become a productive member of society, who, by his example, is helping other challenged youth to reach for their own stars.<sup>65</sup>

#### ABOUT THE AUTHORS

Barbara S. Hughes is a partner with Hill, Glowacki, Jaeger & Hughes, LLP in Madison, Wisconsin and currently serves on the NAELA Board of Directors. She focuses her practice in the areas of elder law, estate planning, special needs trusts and other planning with and for disabled persons, estate and trust administration, marital property law, and also consults in family law matters involving disability. Judith C. Saltzman is a shareholder at Hickman and Lowder Co., LPA in Cleveland, Ohio. Her firm provides a broad range of legal services to individuals with disabilities, to elderly persons, and to public and private agencies which provide services to them. Ms. Saltzman focuses her practice in the area of education law on behalf of children with special needs.

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65. Hughes is grateful to her client and his mother for presenting this challenge, for their willingness to share their subsequent experiences and suggestions with her, and for their encouragement to share all of this with other attorneys.

The following document has been adapted by Attorneys Barbara S. Hughes of Madison, Wisconsin and Judith C. Saltzman of Cleveland, Ohio from a document drafted by Attorney Hughes of Hill, Glowacki, Jaeger & Hughes, LLP, Madison, Wisconsin with input received from school district legal counsel for use in several specific cases for clients in the Madison Metropolitan School District. Local vocational/technical schools and the University of Wisconsin have previously accepted the original instrument. The sharing of this document is subject to the express understanding that legal counsel should review and modify the document as appropriate in other cases.

*This document is for informational purposes only, and does not constitute legal advice. The authors and their law firms expressly disclaim all responsibility for all consequences of use of this material.*

SPECIAL DURABLE POWER OF ATTORNEY FOR MATTERS  
CONCERNING EDUCATION

I, \_\_\_\_\_, hereby designate my *relationship, name*\_\_\_\_, as my Agent to handle the control and management of my education on my behalf.

I designate my *relationship, name*\_\_\_\_, as my alternate Agent to handle the control and management of my education on my behalf if my Agent is ever unable or unwilling to serve. An alternate Agent shall have the same powers under this instrument as the initial Agent.

My Agent is authorized in my Agent's sole and absolute discretion, with respect to the control and management of my education, to do every act and thing whatsoever necessary, proper or convenient to be done as fully as I might or could do for myself. By the granting of this Special Durable Power of Attorney for Matters Concerning Education, I intend to give my Agent the broadest possible powers to represent my interests in all aspects of any dealings or decisions involving my education.

The following powers are specifically included, but the listing of such specific powers shall not restrict the exercise of the broad and general powers granted:

1. To provide opportunities for me to engage in any public and/or private educational programs.
2. To make decisions for me concerning my education.
3. To provide opportunities for me to engage in any recreational activities having an educational purpose.
4. To investigate and arrange for opportunities for me to engage in educational activities providing occupational training.
5. To enroll me in any educational programs.
6. To authorize any services for me that are designed to provide me with educational benefit and/or access to a free, appropriate public education in public school as provided for in the Individuals with Disabilities Education Act.

7. To negotiate and approve on my behalf reasonable accommodations in education services as required under Section 504 of the Rehabilitation Act of 1973.

8. To have access to my school records and other personal education information. The scope of this power shall also extend to confidential records and information, whether prepared by school personnel or by third parties, including but not limited to medical services providers, psychological services providers, assistive technology providers, speech, physical and occupational services providers, social work providers, and any provider of durable medical equipment.

*The authors recommend having the client execute a HIPAA release to facilitate coping with stringent health care records privacy requirements.*

9. To attend and participate in all school meetings and conferences pertaining to me.

#### REVOCATION OF POWER OF ATTORNEY

I may revoke this Special Durable Power of Attorney for Matters Concerning Education by a writing signed and dated by me.

#### RELEASE OF THIRD PARTIES

In the absence of actual notice that I have revoked this instrument, no person, school district or its personnel, organization, corporation, or other entity who deals with my Agent shall incur any liability to me, my estate, my heirs, or my assigns for permitting or facilitating my Agent in the exercise of the authority granted under this instrument. I hereby release all such persons, organizations, corporations or other entities from any liability arising from their reliance on this instrument.

#### PHOTOCOPIES

I authorize that photocopies of this instrument may be made, and that these photocopies shall have the same force and effect as the original.

#### EFFECTIVE DATE AND GOVERNING LAW

This instrument shall become effective immediately, and it shall not be affected by my subsequent disability or incapacity. This instrument shall become null and void in the event of the death or incapacity of the Agent. This instrument shall be governed by the laws of the State of \_\_\_\_\_.

Signed on \_\_\_\_\_, 2005.

\_\_\_\_\_  
Name of Principal

STATE OF \_\_\_\_\_)  
: ss.  
COUNTY OF \_\_\_\_\_)



*Use your state specific Acknowledgment and/or the Acknowledgment required by the state in which the power will be used.*

\_\_\_\_\_  
Notary Public,

[Affix Notary stamp or seal as required by your state].

We certify that the foregoing instrument was on the date set forth above signed by \_\_\_\_\_ in the presence of us; and that at [his/her] request and in [his/her] presence, and in the presence of each other, we subscribed our names as attesting witnesses thereto.

\_\_\_\_\_ of \_\_\_\_\_  
\_\_\_\_\_ of \_\_\_\_\_

This document was drafted by:

Attorney name

Bar number

Firm name

Firm address

Firm phone