The IDEA Right of Informed Consent:  
Its Origin, Meaning and Use  
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I. INTRODUCTION

“The goals of IDEA include ‘ensur[ing] that all children with disabilities have available to them a free appropriate public education” and "ensur[ing] that the rights of children with disabilities and parents of such children are protected.’” Winkelman v. Parma City Sch. Dist., 550 U.S. 516, 524 (2007). To accomplish this the IDEA (and its predecessor the EHA) did not always recreate or invent new rights, as it drew its concepts from constitutional and common law, adopting these to educational setting. In the special education process, “[p]arents ... play a significant role in the IEP process. They must be informed about and consent to evaluations of their child under the Act. § 1414(c)(3). ... parents have the right to review all records that the school possesses in relation to their child. § 1415(b)(1).” Schaffer v. Weast, 546 U.S. 49, 53 (2005).

It is not a novel proposition to say that parents have a recognized legal interest in the education and upbringing of their child. See, e.g., Pierce v. Society of Sisters, 268 U.S. 510, 534-535, ... (1925) (acknowledging "the liberty of parents and guardians to direct the upbringing and education of children under their control"); Meyer v. Nebraska, 262 U.S. 390, 399-401 ... (1923). There is no necessary bar or obstacle in the law, then, to finding an intention by Congress to grant parents a stake in the entitlements created by IDEA. Without question a parent of a child with a disability has a particular and personal interest in fulfilling "our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities." § 1400(c)(1).

Winkelman at 529. It is in this context that IDEA’s “informed consent” must be assessed, remembering that there is nothing which alters or directly limits the application of the
constitutional doctrine or its relationship to the constitutional right to manage and control
the up-bringing of one’s child. The IDEA is built on protecting the rights of children and
parents. *Schaffer* at 54; 34 C.F.R. § 300.1 (b). IDEA “creates in parents an independent
stake not only in the procedures and costs implicated by this process but also in the
substantive decisions to be made.” *Winkelman* at 531. Thus the right of consent is intrinsic
to the process but its full application is often ignored in its application. This right is closely
related to the rights of notice and participation, all allowing the consent to operate.

II. CURRENT CONSENT PROVISIONS

The right to informed consent is an explicit and embedded provision in IDEA and
Section 504, intrinsic to the school district’s ability to evaluate, place, and develop a
treatment plan. IDEA consent is defined as:

(a) The parent has been **fully informed of all information relevant to the activity for which
consent is sought**, in his or her native language, or other mode of communication;

(b) The parent understands and agrees in writing to the carrying out of the activity for which his or
her consent is sought, and the consent describes that activity and lists the records (if any) that will be released
and to whom; and,

20 U.S.C. 1414(a)(1)(D); 34 C.F.R. § 300.9 (2008) (emphasis supplied). OSEP explains:

The definition of consent requires a parent to be fully informed of all information relevant to the activity for which consent is sought. The definition also requires a parent to agree in
writing to an activity for which consent is sought. Therefore, whenever consent is used in these [2006] regulations, it means that consent is both informed and in writing. The meaning of
the terms “agreed” or “agreement” is not the same as consent.

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1 See *In re: Letter to Durheim*, 27 IDELR 380 (OCR 1997).
“Agree” . . . refers to an understanding between the parent and public agency about a particular question or issue, which may be in writing, depending on the context.

Comments, 71 Fed.Reg. 46551 (2006). Thus OSEP draws some distinction between agreement and consent though perhaps this is limited to method of expression of consent - i.e., that these be in writing for consent.

These provisions are supplemented by 34 C.F.R. § 300.300(b)(2) which requires a public agency to make “reasonable efforts” to obtain the informed consent for the initial provision of services and related services and for evaluation. See also, 71 Fed.Reg. 46543 (2006). Section 504 has also been held to have an informed consent provision embedded in 34 C.F.R. § 104.36 (2000) its general procedural rights regulation. FERPA and IDEIA require informed consent to release of records and have a list of exceptions which include emergencies, research, law enforcement and in response to orders and subpoenas if notice is provided. See, 34 C.F.R. §§ 99.30 and 99.31, and. 34 C.F.R. §§ 300.610 et seq.

Inherent in any right to give consent is the prerogative to withdraw or revoke it:

(c)(1) The parent understands that the granting of consent is voluntary on the part of the parent and may be revoked at any time.

(2) If a parent revokes consent, that revocation is not retroactive (i.e., it does not negate an action that has occurred after the consent was given and before the consent was revoked).

(3) If the parent revokes consent in writing for their child's receipt of special education services after the child is initially provided special education and related services, the public agency is not required to amend the child's education records to remove any references to the child's receipt of special education and related services because of the revocation of consent.
IDEA defines who is seen as the “parent,” the consent given, in 20 U.S.C. § 1401(23)(2004); 34 C.F.R. § 300.30(2006). This is broader than under the common law and in many state special education statutes for functional purposes and to move the IEP process forward. It is the (1) biological or adoptive parent; (2) a foster parent unless the state prohibits them from acting as the parent; (3) a guardian; (4) a person “acting in the place of the biological parent” or who is “legally responsible” for the child; (4) the surrogate parent. To protect schools from being embroiled into custody situations and court orders, there is a presumption that a parent remains the parent unless there is a specific provision in a court order assigning the sole power to make educational decisions. 34 C.F.R. § 300.30(b)(2006). States may extend or increase this definition.

**III. THE RELATED RIGHTS OF INFORMATION AND NOTICE**

Inherent to the right of informed consent are the mandatory notice provisions which assume that the parent is being provided necessary information. Thus the Notice of Procedural Safeguards, 34 C.F.R. § 300.504 (2006) must be given at critical decision making times, i.e., at least yearly, and on referral for evaluation, on disciplinary measures, when seeking due process and upon request. § 300.504(a)(1)-(4). This is supplemented by the substantive informational notice at 34 C.F.R. § 300.503(2006), generally called the “Prior Written Notice” (PWN). This must be given when the LEA “proposes to initiate or change the identification, evaluation, or educational placement,” or FAPE, or refuses to make such changes. § 300.503(a). It has explicit content requirements in § 300.503(b).

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2 This portion of the regulation was re-written after notice and comment in 2008, effective January 1, 2009. It clarified the response to revocation of consent.
These tie to the right to receive the IEP and to have access to records before IEP Team meetings and hearings. 34 C.F.R. § 300.613(a)(2006). To facilitate access to records, parents must receive notice of their right to receive and review records. 34 C.F.R. § 300.612(2006), and when records are sought or released. Other rights and events have embedded notice and agreement provisions.

IV. THE APPLICATION OF CONSENT IN IDEA

A. Inventory of the Applications of IDEA Informed Consent.

1. Informed consent must be obtained before the initial provision of special education and related services. 34 C.F.R. § 300.300(b)(1). See In re: Letter to Gant, 39 IDELR 215 (OSEP 2008) (requires all information needed to make decision) (failure to respond is absence of consent). Transfers to new states restart initial placement consent. In re: Letter to Champagne, 53 IDELR 198 (OSEP 2008).

2. Consent must be obtained before initial evaluations and/or re-evaluations. 34 C.F.R. §§ 300.300(a)(ii) and 300.300(c). Note: Screening, as compared to evaluation, does not require consent. See, e.g., 71 Fed.Reg. 46639 (August 14, 2006). Questions arise concerning what testing requires consent, generally resolved by tests that have individual applicability, not those given to the group, grade or class as a whole. See In re: Letter to Black, 17 IDELR 181 (OSEP 1990) (consent not required to group and generally administered tests).

3. Consent to use parents’ public benefits or insurance. 34 C.F.R. § 300.154(d)(2)(iv). See In re: Letter to Thompson, 34 IDELR 8 (OSEP 2000); In re: Letter

3 There have been questions about the duration of consent on this issue. This is generally viewed as requiring additional and reoccurring consent as the rules now say consent is required “each time that access” to the benefit is sought.
4. Consent must be obtained to release educators and therapists from IEP meetings. 34 C.F.R. § 300.321(e)(2). This is known as the right of “excusal.” 4 This has a built-in “informed” provision as the staff seeking excusal must present a prior written report to the parents for consideration of excusal. 34 C.F.R. § 300.321 (e)(2)(ii).

5. Consent to alter the maintenance of placement. 34 C.F.R. § 300.518(a). After the case law interpreted a parent “prevailing” in an administrative hearing as an agreement between the state and the parent as to the parent’s sought placement, this was changed to presume this agreement under IDEA 2004. 34 C.F.R. § 300.518(d)(2006).

6. Consent after notice and prior to release of records. 34 C.F.R. § 300.612 and 300.622. See FERPA, 34 C.F.R. §§ 99.31 and 99.33; In re: Letter to Schaffer, 34 IDELR 151 (OSEP 2000). This differs from notice of release of records, an independent right.

7. Consent to waive the resolution meeting. 34 C.F.R. § 300.510(b)(3).

8. Consent for IEP meetings time and dates. 34 C.F.R. § 300.322(a)(1) and (2).5

9. Consent to the location of IEP Team Meetings. 34 C.F.R. § 300.322 (a)(2). 6

10. IDEA 2004 allows IEPs to be amended in writing outside an IEP meeting. This

4 There is some ambiguity as to the required IEP Team members. It is argued by districts that the list in § 300.321 (a)(i)-(7) is inclusive and that others, i.e, other teachers and therapists, are not subject to excusal. This ignores the provisions of § 300.321 (a)(6) which allows other individuals who have knowledge or special expertise...including related services personnel.” Thus a parent should appoint such members and seek their attendance.

5 The regulations and statute use the phrase “agree” on this right. In practice, it is a consent as the meeting time and place is instigated by the District, subject to objection, and in that case, to a subsequent agreement. Consent is presumed if a reasonable effort is made if the parent does not respond. See 34 C.F.R. § 300.321(a). The parents preserve their rights by objecting and offering alternatives while saying they “want to attend all meetings.”

6 This too is stated as an “agreement.”
is also a form of informed written consent. See 34 C.F.R. § 300.324(a)(4) and (6).

11. Parents decide if child attends the IEP meeting. 34 C.F.R. § 300.321(a)(7).

12. Parents may consent to part of program and reject other parts. 34 C.F.R. § 300.300(d)(3).

13. Parents decide if hearing is open or closed, if the child attends and the nature of the record they receive. 34 C.F.R. § 300.512(c).

14. The use of an IFSP as a substitute for a new IEP requires informed consent. 34 C.F.R. § 300.323 (b)(2). This must include being informed of the differences between an IEP and IFSP. See In re: Letter to State Directors, 33 IDELR 158 (OSEP 2000).

B. **IDEA is Silent on the Right to Consent in Several Areas**

IDEA omits an explicit provision for consent to the annual review or a change in the program or placement at that junction. Presumably, this means that the changes can be made at the annual review without consent after notice, in the absence of due process. The parental right is to seek due process and invoke the maintenance of placement.

C. **FERPA Rights to Consent**

FERPA has its own notice and consent provisions. Generally, prior notice to release is required, as it is in the Notice of Procedural Safeguards under IDEA, and consent is necessary. See 34 C.F.R. § 99.30. The written consent must specify the records, the purpose of the disclosure, the parties to whom it may be made, and allow for a copy to the parent. In the disclosure of records to LEAs and from LEAs, remember they are not HIPPA entities.

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7 The revocation of consent rules were rewritten in 2008. See 73 Fed. Reg. 73006 (December 1, 2008). These comments loosely address revocation, identifying that consent should be to the entire program on initial placement and then revocation is to the entire program. 73 Fed. Reg. 73011. This ignores the partial consent provision in 34 C.F.R. § 300.300(d)(3) and is overly broad.
and records lose these protections once obtained by the LEA. 34 C.F.R. § 99.33 has a long list of exceptions and broadly defines the educational agency to allow intra-agency disclosures for educational reasons. Exceptions include employees and contractors, the United States, the SEA, groups conducting studies, accrediting organizations, pursuant to court order or subpoena, when the parent brings an action or proceeding, in emergencies, in criminal situations, in disciplinary situations. FERPA provisions protect redisclosure, § 99.34, and has provisions regulating certain specific disclosures. §§ 99.34-99.38.


Prior to the amendments in 2004 and the 2006 regulations, it was not clear when a district could seek due process. In re: Letter to Aden, 38 IDELR 267 (OSEP 2003) reaffirmed OSEP’s long held position that IDEA would not support a claims of a district to override a refusal to consent to initial services. This was addressed in IDEA 2004 which allows school districts to avoid IDEA liability if the parent refuses an evaluation or consent to the initial provision of services. The LEA may seek due process to obtain the evaluation but not to force initial placement. The district will not be considered in violation of a requirement to provide FAPE in the absence of a response or affirmative consent to services. 34 C.F.R. § 300.300(b)(4)(i). The district is not required to convene a meeting or provide services for which consent is not obtained, Section 300.300(b)(4)(ii), but “if they wish to change an existing IEP but the parents do not consent, or if parents refuse to allow their child to be evaluated,” districts may seek due process. Schaffer, 546 U.S. at 533.

OSEP and the common interpretation of the EHA/IDEA allow states to provide more rights to children and parents. Thus, states may provide broader rights of consent. 34 C.F.R. § 300.300(d)(2). Schools may pursue reevaluations through due process. Id.; 34
C.F.R. § 300.300 (c)(1)(ii).

The case law which has extended the parent’s duty to agree or allow a re-evaluation. See *M.T.V. v. DeKalb County Sch. Dist.*, 446 F.3d 1153, 1160 (11th Cir. 2006). Some of these cases invoke penalties against parents for withholding consent. See *Address v. Cleveland Indep. Sch. Dist.*, 64 F.3d 176, 178 (5th Cir. 1995). This is contrary to the analysis that the sufficiency of the information for the evaluation, and, the scope of the evaluation is subject to the LEA’s request for due process, 34 C.F.R. § 300.300(a), (c), and a hearing right as to the need and scope of the reevaluation. See *Holland v. Dist. of Columbia*, 71 F.3d 417 (D.C. Cir. 1995). The source of these cases pre-dates the standards of IDEA 2004.

E. **Presumed Consent**

IDEA can override or presumes consent, either in the absence of a response or in the absence of a due process request. There is no explicit provision requiring consent to a change in services of an annual review and to maintain the earlier programs, presumably due process and the maintenance of placement must be enforced. Previously, amendments to the IEP could be implemented without consent in the absence of due process, *In re: Letter to Aden*, 38 IDELR 267, 4 ECLPR 443 (OSEP 2003). IDEA now requires written consent or the agreement of the whole team for amendments. Procedures provide for holding meetings in the absence of a response, 34 C.F.R. § 300.322 (d). The failure to respond can be an implied consent to reevaluations. 34 C.F.R. § 300.300(C)(2).

F. **Who Exercises the Right to Consent?**

The parents exercise the right to consent. Under IDEA, a parent is a parent unless that is altered by an order by of a state court. 34 C.F.R. § 300.30. *See Taylor v. Vermont Dept. of Ed.*, 313 F.3d 768 (2nd Cir. 2002); *Navin v. Park Ridge Sch. Dist.* 64, 270 F.3d 1147
IDEA has an age of majority rule so the right of consent shifts to the child. 20 U.S.C. § 1415(m) (2004). Parents retain rights of participation.

G. The Right to Condition or Limit Consent

IDEA is not explicit on many traditional views of the right of consent. Thus the practice is that schools draft consent forms and present them. In all other forums, one could object to the scope of consent or provide conditions on the consent. There seems no basis for concluding that the parent must consent on the district’s terms, though that is often implied into the practice. But see, G.J. v. Muscogee Sch. Dist., OSAH-DOE-0908379-106-Miller (SEA Ga. 2008), on appeal.

H. The Right to Consent to Certain Services and Evaluations and Not to Others

IDEA allows that a “public agency may not use a parent’s refusal to consent to one service or activity ... to deny the parent or child any other service, benefit or activity” except as provided within the rule. 34 C.F.R. § 300.300 (d)(3)(2006). This is often also functionally ignored in the evaluation-placement-IEP interplay.

I. IDEA Regulates the Revocation of Consent.

A parent may revoke consent at any time. 34 C.F.R. § 300.9(c)(1). This revocation is prospective and does not negate actions taken previously. OSEP previously said that the right to revoke consent to initial placement ended when the child was placed, In re: Letter to Williams, 18 IDELR 534 (OSEP 1991), but now the parent may revoke consent to all services. § 300.9(c); 73 Fed. Reg. 73009-73010. The agency must provide prior written notice and continue services to allow the exercise of consent. Id. The district may not challenge a full revocation in due process. Id.
V. THE ELEMENTS OF INFORMED CONSENT

The statute and regulations identify that the parent has the right to “all the information” relative to the activity for which consent is sought. This may mean:

1. **A complete description of the activity.** As to an IEP, the who, what, when, where. All the statutory elements of the duration, location, initiation and frequency of services. The required written notice under 34 C.F.R. § 300.503(b). This should include how it provides FAPE, *i.e.*, how standards of the SEA are met, 34 C.F.R. § 300.17(b), and how it is in “conformity with” the IEP, § 300.17(a).

2. **Right to understand /Informed Consent.** § 300.9 requires the parent “understand” and consent be sought in the parents’ native language. *In re: Letter to Boswell, 49 IDELR 196 (OSEP 2007)* limits the *per se* duty to translate all IEP documents, though it references the consent translation obligation. Note: This duty may arise under Title VI of the 1964 Civil Rights Act.

3. **Information of Evaluation and Evaluation Requests.** Requests for evaluations require informed consent, so the question is the scope of the information. The right to PWN underpins all requests for consent and agreement, as the basic tool for providing information. The questions of the extent of information necessary as to the scope of the evaluation lingers. Parents have rights to object and withhold consent when their questions as to the evaluation are not answered. *Holland v. Dist. of Columbia, 71 F.3d 417 (D.C. Cir. 1995)*. Yet OSEP has not required explicit pre-notice of all test instruments. OSEP. It posts and many states provide a listing of potential assessment and evaluation instruments to use as a facade to actual notice. These are generally inadequate and often completely fail to address the specific type of evaluation at issue. Parents can avoid this morass by simply
seeking to meet with the evaluator in advance and discussing the assessment, and if they
are not satisfied, they can revoke consent.

4. Alternatives. This is part of the common law and of many statutory provisions
of informed consent especially tort and medical consent laws. This is also embedded in the

5. The right to disagree. Under the common law, the right to consent is meaningless
without the right to withhold consent or to object. The information includes necessary
information on the risks of withholding consent. This supports the two notice requirements
and the placement alternatives under IDEA. The risks may arise in the placement rules as
the risk of harm from the placement. 34 C.F.R. § 300.116(d).

6. Written notice. Also related to no. 1, above. Contents of notice at 34 C.F.R. §
300.503(b)(2006). This is the heart of any consent.

7. The Right to Express Dissent or Objection. This is a common law element of
informed consent. It includes substitute decision making and means consent is not
presumed. It also means that if consent is sought, the answer, even if it is a rejection, is
given dignity and effect.

VI. Other Sources of the Right to Consent.

IDEA did not invent the right of consent, nor supplant many of the rights which
otherwise exist. Other sources of law should be used to address consent and include:

1. The right to consent to medications and treatment. The concept of consent to
treatment and medication overlaps with the IDEA consent rights. Schools may not require
medications, nor limit services in the absence of medication. Parents are presumptively the
Children have protected liberty interests in physical integrity. *Id. See also, Youngberg v. Romeo*, 457 U.S. 307, 315-316, 319 (1982) (incompetent person maintains liberty interest); *Mills v. Rogers*, 457 U.S. 291 (1976). At its purest form, this emerges from the right to maintain and control one’s own physical integrity. *Mills*, 457 U.S. at 294, n.4 (consent to treatment); *Thompson v. Oklahoma*, 487 U.S. 815, 825 n. 23 (1988). This interest protects the unnecessary invasion by government and places a high standard on enforced treatment. *Mills*; *Cruzan v. Missouri*, 110 S.Ct. 2841 (1990). Under the common law and first amendment, if there is a qualified right to resist treatment absence informed consent, including death threatening refusals, then there should be a right to resist non-consensual special education treatment, especially if it intrudes on physical autonomy. IDEA presumes, as the Court in *Parham* held, that the parent acts in the child’s interest. 73 Fed. Reg. 73011-12. Many of the professions maintain this right of consent in ethical rules.

IDEIA 2004 excuses the provision of FAPE in the absence of consent to evaluation and placement. This has a different analysis than the issue arising under the right of privacy and physical integrity, and does not reach the question as to the continued invasions once consent is partially withdrawn, or the right of a school to seek a hearing to enforce non-consensual treatment when the parent does not want to remove the child from special education but disputes the interventions, nor provide a heightened standard of review such as in *Cruzan*, or require a showing of compelling state interest. The maintenance of informed consent would seem to also apply constitutional limitations. Perhaps IDEA needs to be enforced with their heightened burden when districts seek to enforce non-consensual services. This is abstract from not providing sufficient services.

2. **Consent to district access to private professionals and education records** is not required under IDEIA. Consent may be granted with any limitations deemed necessary,
including limiting contacts without involving the family and other restrictions felt appropriate. Remember, the consent should be defined in areas of otherwise complete parental control by the consent that is voluntarily given.

3. **Right to Transfer Consent**, by contract or power-of-attorney to others. This right seems to exist under the “parent” definition of § 300.30. It rises to the level of allowing post-competency directives after *Cruzan* for termination of life, and has broad implications.

**VII. Areas In Which To Use the Right of Informed Consent.**

IDEIA is not explicit on how decisions are made at IEP meetings. The parent is on strong grounds to assert that changes can only occur through informed consent and therefore through the provision of adequate information to allow the parent to grant such consent. This stops short of requiring consensus but places the parental participation and information at the front. Potential specific uses include:

1. The opportunity to observe alternative programs in making placement decisions.
2. Observation of the current placement and information on teachers and aides.
3. Opportunities to meet with evaluators who have conducted evaluations and/or re-evaluations. These conditions can be added to the consent forms and such rights are supported in most ethical standards. Parents should never sign a blank, generic, overly broad consent form.
4. The right of parents to know the actual test instruments to be used, the time, location, and day of the evaluations. This may conflict with an old and ill-conceived OSEP letter and the common law rights of a parent. In *Holland v. Dist. of Columbia*, 71 F.3d 417

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*Another argument is that if the district seeks your consent it cannot later say it was unnecessary. Another conceptually corrupt approach is *Letter to Grimes*, 211 IDELR 187 (BHA 1980), which says those all-inclusive notices are adequate. This and its progeny can be attacked on limiting the current right to informed consent.*
(D.C.Cir. 1995) the Court recognized that the parent right of consent required the district to be explicit as to the evaluation and the procedures. The Court reversed the dismissal and remanded to see if the necessary information had been provided.

5. The right to set specific deadlines not otherwise required or generally provided under the law. This includes deadlines on re-evaluations, the implementation of services, and the completion of tasks such as functional behavior assessment. These can be used as part of consent or as a negotiation when consent is sought.

6. Parent’s rights to have independent professionals observe.

7. The who, what, where, why, and how answered concerning anything for which consent may be sought or appropriate. See also, 34 C.F.R. § 300.503(b) (written notice).

8. The right to know the training and experience of staff.

9. The right to have records and drafts before IEP and eligibility meetings.

10. The right to know the educational environment, including the numbers and general description of the peers in special education and regular education classrooms.

11. The right to establish ESY early in the IEP.

12. The right to have all records and protocols.

13. Access to teacher’s personal notes if these are withheld regardless of FERPA record limitations.

14. The right to put conditions on anything upon which you consent, i.e., to define the scope and extent of your consent.

15. The “methodology” and instructional modifications as part of the “specialized instruction” under 34 C.F.R. § 300.39(b)(3).

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