

**Special Needs Issues in Family Law:
An Overview of Exceptional Children Services for the Pennsylvania Custody
Lawyer**

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Introduction:

Families of exceptional children¹ are provided with services through several unique governmental systems which effectuate the goals of Federal and State statutory law. In these families, the “best interests of the child” may be largely determined by the accuracy of the disability diagnosis, the quality of programming, and the consistency and intensity of specialized services. The welfare of the child may be dependant upon the tenacity of one or both parents in obtaining and maintaining services available through the various agencies.

Parents working together to navigate the system have all they can handle to assure the best possible outcome for their child. In families that are split, with Mom and Dad at odds over parenting styles and philosophies, it may be left to the custody lawyer

¹ Pennsylvania law designates children with special needs as “exceptional children.” The terms will be used interchangeably herein. 22 Pa. Code §1221 (iii)

and, ultimately, the court, to sort out the best interests of the exceptional child. The child's needs may be highly specialized and immediate, of such a nature that failure to act quickly will result in a lifetime's regret, such as where a window of therapeutic opportunity requires early intervention or will be forever lost. The child's needs may be subtle, as when one parent insists that a student's school-day attention difficulties be identified and addressed, and the weekend parent, who does not experience the school difficulties firsthand, disagrees as to the existence of a disability at all.

A starting point to understanding the interests of a child and family with special needs is through an understanding of what is available through the governmental agencies charged with their care. Cost-free services provided to children with special needs, regardless of parental income, are provided through systems implementing Federal and State statutory and regulatory authorities for services to exceptional children. There are three main statutory schemes which comprise what we most commonly consider the exceptional children services system, providing services from birth through age twenty-one: Medical Assistance, Section 504 of the Rehabilitation Act, and IDEA.² While there is overlap, eligibility and mission under each of these statutory schemes is unique to the particular statute.

It is important for the custody practitioner to have a basic understanding of the services offered parents of exceptional children through these three programs for several reasons. Under all of these state and locally administered systems, quality and availability of services is frequently dependent upon the location of the parent's residence. To privately provide these services would present insurmountable costs and, because of the specialized nature of the services, substitute services may be unobtainable privately at

² These statutory schemes relate to those families who are not qualified through poverty programs.

any cost. Fast decisive parental action is sometimes required in order to secure an available service for a child. A change of custody undertaken without an understanding of the service systems could negatively affect the quality of life of the child and family, and risk enormous financial cost to the parents.

A. Title XIX of the Social Security Act: Medical Assistance

1. Overview: Medical Assistance or Medicaid (MA)³ is the federal/state insurance program that pays for health services for low-income children (under age 21) and adults with severe disabilities under age 21⁴. The Pennsylvania Department of Public Welfare (DPW) is in charge of MA through the Office of Medical Assistance Programs. MA has means tested eligibility requirements, with some exceptions, mainly, the “ PH 95 loophole”.⁵
2. The Loophole: In Pennsylvania, exceptional children who qualify for identification as disabled under Social Security Income (SSI) rules of eligibility are eligible for MA unless they have income in their own name.⁶ Income of parents and caregivers is not counted. Income of the child is counted.⁷ This is unlike almost every other state in the country, where parental income is counted.
 1. Counted child’s income:
 - i. Interest or dividends on bank accounts reported under the child’s SSI number.
 - ii. Earnings from the child’s job: If the child is working, a portion of those earnings are counted.⁸
 - iii. Trust funds depending upon how the trust is set up.
 2. Not counted as child’s income:
 - i. Court ordered child support (effective through implementing rule, Operations Memorandum 000-806 effective 9-1-2000) PLEASE NOTE: COURT ORDERED “CHILD” SUPPORT FOR THE BENEFIT OF ADULT “CHILDREN” WITH DISABILITIES IS TREATED DIFFERENTLY AND COUNTED AS INCOME.
 - ii. Inheritances (must be properly addressed): These can be counted as resources.

³ While technically MA and Medicaid are the same program, in common use, the provision of services to exceptional children under the “loophole” is referred to as MA.

⁴ Title XIX of the Social Security Act, 42 U.S.C. §1396 , et seq

⁵ Reference is to Public Health rule 95.

⁶ In 2006 the amount was \$817.00 a month.

⁷ This information is offered for general information only. It is not comprehensive and may not be relied upon in resource planning.

⁸ Note: If the child is over the income limit in earned income, he or she probably would not qualify for ssi eligibility in any event.

3. Eligibility: Eligibility for MA is dependent upon the exceptional child meeting the requirements for SSI eligibility. The SSI listing of impairments is detailed in the regulations.
 - i. The child’s condition must fall within the listing of impairments, and the disability then must be established to significantly limit the child’s ability to perform the basic functions of life.⁹ See regulatory authority for specific requirements.
 - ii. An SSI eligibility determination is required prior to obtaining MA, even when a family is not seeking SSI. Unlike MA, parental income *does* count when determining SSI. Denial must be based upon means-testing, not disability status.
1. Who is a ‘Child’?
 - iii. “For purposes of determining eligibility for services provided by MA, a child is defined as an individual under the age 21 regardless of marital or emancipation status. This does not include an unborn.” Source: Medical Assistance Eligibility Handbook 309.11
4. Services: MA entitles children to all “medically necessary” physical and behavioral health services, whether or not related to the disability category. This includes all routine medical care (such as immunizations or treatment for illnesses), but may also include specialized and costly services.¹⁰
 - i. In Bucks County, as in most of Pennsylvania, MA is a mandatory “managed care” program with contracted HMOs. Behavioral health is provided through a separate managed care organization.
 1. Each county has only one behavioral health provider. In Bucks County, it currently is Magellan Behavioral Health.
 - ii. Behavioral Health Services: Behavioral health services, which can be extremely costly if privately obtained, are available through MA for children with an established need. These include wraparound services, medication for behavioral problems, residential and partial hospitalization programs.
 1. “Wraparound” is frequently seen in families as the provision of Therapeutic Staff Support (TSS), who are trained individuals who provide one on one support to exceptional children with behavioral or emotional problems in home, community, or school settings.
 - a. In autism cases, behavioral services may include specific targeted intensive therapies, such as ABA.
 - iii. Physical health therapies provided through MA may include in home nursing, communication or other technological devices,

⁹ The perspective of the lawyer is to find a category into which the child can be fit, rather than merely seeing if the identified disability is on the list.

¹⁰ 42 USC § 1396 (r) (5)

- respite service for parents, or personal assistance with basic activities of living.
- iv. Services such as these are frequently irreplaceable through any other private system, due to cost, availability of staff, and training.
5. Documents: The documents provided with MA services may include a comprehensive behavioral assessment, a physical assessment and treatment plans. In addition, if there have been contested service plans, there may be appeals documents and findings.
 6. Contests: May include disputes over denials of eligibility, disputes over the intensity of services or types of services, disputes over the medical necessity of treatments.
 - i. All appeals of decisions made by managed care must be undertaken within strict time limits. There are even stricter appellate time limits if the clients wish to maintain a level of service the provider is proposing to discontinue.
 - ii. HMOs also have internal grievance procedures by which disputes can be resolved.
 7. Special Education and MA- Overlapping entitlement issues: Services available through MA overlap with services which are necessary for purposes of special education and, similarly, may overlap with support services for students within public schools. Frequently, the question of what is an educational need or a medical need or an emotional support need is unclear.
 - i. The family of a child is not required to await the outcome of a dispute between providers when entitled to a service. When a child qualifies for a service from both systems, they are entitled to the service from either system.¹¹
 - ii. When a child is entitled to services from MA and the school districts, MA, by law, is the “payor of first resort” and the Districts are entitled to MA reimbursement.¹²
 1. This does not mean that the child must await the results of the dispute. The child remains fully entitled to the service from each provider separately.
 8. Further Information: The Pennsylvania Department of Public Welfare administers the MA system for exceptional children. The comprehensive administrative rules currently in place are found in the Medical Assistance Handbook, available through the Department of Public Welfare website at <http://www.dpw.state.pa.us/>. This handbook is frequently updated and a practitioner should check for updates before relying upon the published provisions of the Handbook alone.
 1. Magellan Behavioral Health procedures may be found on the Magellan web page or by contacting the provider.

⁸ 20 U.S.C. §1412 (a)(12)(B)(ii)

¹² 20 U.S.C. §1412(a)(12)(A)(i) (payor status of MA precedes financial responsibility of the local educational agency)

B. Section 504 of the Rehabilitation Act

1. To be eligible for services under Section 504 of the Rehabilitation Act,¹³ a child must be a child of school age with a disability.
 - a. Students who do not meet the definition of disability for purposes of IDEA (which follows) may still be individuals with disabilities for purposes of Section 504.
 - b. Section 504 is an antidiscrimination act, and provides that those qualifying students are entitled to reasonable accommodations from the public schools and other recipients of federal funds.
 - c. For students eligible under IDEA, compliance with the provisions of IDEA will meet the requirements of Section 504.
 - d. Students qualifying under Section 504 and not under IDEA will be provided with a “Service Agreement” or “504 Plan” which will state the services that will be provided to enable the child to participate fully in the school program and extracurricular activities.
 - e. For example, a student with diabetes may not need instruction to differ from that received by the regular education students, but may need accommodations and support to be able to effectively monitor and control blood sugar, and a plan for possible crisis control.

C. 20 U.S.C. §§1400 *et seq.*: INDIVIDUALS WITH DISABILITIES EDUCATION ACT: IDEA

1. Overview: The Individuals with Disabilities Education Act (known as “IDEA”) is a funding statute. State recipients of the special education federal funding are required to put into effect policies and procedures to ensure that:
 1. all children with disabilities residing in the State, including children in private schools, regardless of the severity of their disabilities, and who are in need of special education and related services, are identified, located and evaluated, and;
 2. all eligible children are provided with a free appropriate public education (FAPE).
 3. Federal regulations implementing IDEA are located at 34 C.F.R., Part 300.
 4. Pennsylvania has implemented the IDEA through 24 P.S. §13-1371 & 1372. The regulations are located at 22 Pa. Code Ch. 14.

Entitlement under IDEA

Infants and Toddlers: Individuals under 3 years of age who need early intervention services because:

1. child is experiencing developmental delays in one or more of the following areas, or
2. child has a diagnosed physical or mental condition which has a high probability of resulting in developmental delays in one or more of the following areas:
 - cognitive
 - physical

¹³ 15 Pa. Code Section 15 implements Section 504 of the Rehabilitation Act in Pennsylvania

- communication
 - social
 - emotional
 - adaptive
3. at States' discretion, may include at-risk infants and toddlers. Source 20 U.S.C. §1432

School Aged: A student of school-age meets the definition of a "child with a disability" and is eligible under IDEA if he or she falls within one or more of the following disability categories:

1. mental retardation
2. hearing impairments, including deafness
3. speech or language impairments
4. visual impairments, including blindness
5. serious emotional disturbance ("emotional disturbance")
6. orthopedic impairments
7. autism
8. traumatic brain injury
9. other health impairments
10. specific learning disabilities, *and*,

Is in need of specially designed instruction and related services. Source 20 U.S. C. §1401(3)

2. Key concepts in special education under IDEA:

1. FAPE: A free appropriate public education is defined as special education and related service, at public expense, that comply with the procedural and substantive requirements of IDEA, and is reasonably calculated to provide meaningful educational benefit.¹⁴ 20 U.S.C. §1401(22)
 - i. The Supreme Court recently restated the definition of "FAPE":

“The Act defines a “free appropriate public education” pursuant to an IEP to be an educational instruction “specially designed . . . to meet the unique needs of a child with a disability,” §1401(29), coupled with any additional “‘related services’ ” that are “required to assist a child with a disability to benefit from [that instruction],” §1401(26)(A). See also §1401(9). The education must, among other things, be provided “under public supervision and direction,” “meet the standards of the State educational agency,” and “include an appropriate preschool, elementary school, or secondary school education in the State involved.” *Ibid*. The instruction must, in addition, be provided at “no cost to parents.” §1401(29). See generally *Board of Ed. of Hendrick Hudson Central School Dist., Westchester Cty. v. Rowley*, [458 U.S. 176](#) (1982) (discussing the meaning of “free appropriate public education” as used in the statutory precursor to IDEA).” *Winkelman v. Parma City School District*, 550 U.S. ___ No. 05-983, (2007)
2. ER (evaluation report): Identification of the child and programming are both based upon an evaluation, conducted by the educational agency, which assess the child: “in all areas related to the suspected disability, including, if appropriate... social and emotional status...communication

¹⁴ *Ridgewood Board of Education v N.E.* 172 F.3d 238 (3d Cir. 1999)

status...” (34 CFR§300.532) and employing “(a) variety of assessment tools and strategies ...to gather relevant functional and developmental information (§300.532)... needed for effective programming for the child” (§300.533).

3. LRE (least restrictive environment): IDEA requires states to ensure that: “to the maximum extent appropriate, children with disabilities...are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability ...is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.” 20 U.S.C. §1412(A)(5).
4. FREE: Free, as used in the definition of FAPE, means fully at public expense . § 1412(a)(10)(B). If a private facility or school is necessary to meet a child’s needs, the program must be provided.
5. IEP (Individualized Education Program): Each identified exceptional child must have a written IEP. It is the cornerstone of the special education system.
6. IEP Team: IDEA requires that a team of certain legally designated individuals develop the IEP for an exceptional child. Parents are part of this team, and parents are further permitted to be accompanied by individuals they believe useful participants in the process.
7. IEP Meeting: IDEA requires meetings for several purposes, the most important of which may be the IEP meeting at which the IEP is developed. A parent may call an IEP meeting when he or she believes it necessary to readdress the program.
8. PWN (Prior Written Notice): The procedural requirements of IDEA require that Parents be provided with prior written notice when key actions are to be taken involving their or their child’s special education rights. These require that action be taken within a specified period of time.
 - i. PWN is required when, among other things, the LEA proposes to change an eligible student’s placement.
9. LEA (Local educational authority) The LEA holds the funding decision-making authority for the IEP team and is responsible for provision of the program. For school aged children, the LEA will usually be the school district. For preschool aged, the state has designated the local IUs as LEA.
10. IU (Intermediate Unit) – Intermediate Units were established by the state legislature to serve as regional offices for special education services. There are 29 IUs in Pennsylvania and each is unique. IUs serve as LEA for preschool services and may be used, by Districts, for provision of school aged services.¹⁵
11. Due Process –“Due Process” is the confusingly named first level of administrative dispute of a proposed action by the LEA. Initiating this action is commonly referred to as “requesting due process,” which has an entirely different meaning to non-education lawyers. Due process is

¹⁵ 22 Pa Code Ch. 17 et seq

initiated by the filing of a Notice of Complaint, and may be initiated by either the LEA or the Parent. A due process hearing is a full evidentiary hearing before a special education hearing officer, an employee of the Pennsylvania Department of Education. Appeals from the hearing officer decision are taken to Federal District Court or Commonwealth Court.

- i. Claims by parents for past denial of FAPE result, when successful, in an award of “compensatory education”, which is, usually, a fund detailed for educational expenses such as will compensate the student for the educational benefit he had failed to receive during the period of the denial.
 - ii. Claims by parents for prospective programming will result, when successful, in a directive for the LEA to develop an IEP in accordance with parent’s or parent’s experts’ requests, or private placement, where necessary.
 - iii. Claims by parents for reimbursement of tuition expense, or private provision of other services will, when successful, result in an order for reimbursement for parental outlay necessitated as a result of the denial of appropriate services or education by the LEA.
12. Parental Rights under IDEA: Parents have enforceable rights under IDEA, not just on their child’s behalf, but as parties in interest in their own right, as parents.¹⁶
- i. Where consent is mandated by IDEA, an LEA is required to obtain the consent of only one (“a”) parent with legal custody of the student, although PWN is required to be provided to each parent with legal custody.
 - ii. Similarly, each parent with legal custody has the right, individually, to object to a proposal, reject a program, or request administrative redress.
3. There are several key procedural stages in the process of the development and delivery of FAPE under IDEA. At each of these stages, parental involvement and decision-making is paramount.
1. Stage One: Initial evaluation: If the LEA wants to evaluate a child it suspects of a disability, it must send the parents PWN, and request parent’s consent.
 - i. If the parent refuses consent to the first evaluation, the LEA must request a hearing and obtain an order from a special education hearing officer before the evaluation can take place.
 - ii. The LEA is required to obtain parent consent prior to conducting a reevaluation as well, but if the LEA can establish that it took reasonable measures to obtain the consent and the parent has failed to respond, the district may proceed without consent.
 - iii. Parents may request a reevaluation.
 - iv. Parental contribution to evaluation: The LEA will request parental input into the evaluation, including, in some instances, parents

¹⁶ Winkleman, supra.

response to various ratings scales supplied through standardized testing protocols.

2. Stage two – initial identification.
 - i. In the evaluation report, as a result of the testing conducted, the evaluator may recommend identifying a student as eligible for special education under IDEA, may decide that the student does not qualify under IDEA but is a student with a disability entitled to accommodations under Section 504 of the Rehabilitation Act, or may recommend finding the student ineligible, either with a non-qualifying disability or without a disability.
 1. The parent has the right to disagree with the ER.
 2. The parent has the further right to request an independent evaluation at LEA expense.
 3. Following this request, the LEA must either provide the independent evaluation or request a hearing in defense of the LEA ER.
 - ii. If the evaluation report identifies the student as eligible under IDEA, an IEP will be developed.
 - iii. If a parent refuses initial provision of special education under IDEA, the District may not override this refusal.¹⁷
3. Stage three – development of an IEP: An IEP team develops an educational program for the student, then commemorates it in the written IEP.
 - i. While it is beyond the scope of this paper to address the development of an IEP in detail, an overview of the following general requirements may be useful.
 1. An IEP establishes present educational levels for students – this describes how the child’s disability affects his or her involvement and progress in the general curriculum;
 2. It establishes “measurable” annual goals (and short term objectives, if necessary) and a method for evaluating and reporting the achievement results for these goals in a manner understandable for parents;
 3. It describes the specially designed instruction that students will receive to deliver these goals;
 4. It describes the modifications that are needed to enable the child to participate in state or district wide assessments;
 5. It describes what related services the student needs in order to benefit from his or her program.
 - ii. A parent with legal custody may request an IEP meeting whenever he or she feels it necessary to address the program and placement.
 - iii. Under the statutory and regulator scheme, each parent with legal custody has individual rights under IDEA’s procedural provisions.
4. Stage four: The NOREP. Parents are involved in the development of the IEP through the IEP meetings. Following the team’s decisions and the

¹⁷ 20 U.S.C. § 1414(a)(1)(D)(ii)(II).

drafting of the final version of the IEP, the Parents will be provided with PWN in the form of a NOREP (notice of recommended educational placement). This is a formal notice form which provides space for parents to either agree or disagree with the IEP being proposed. If parents disagree, they are provided with options to check, one of which is mediation, and one of which is due process.

1. If parents do not respond to the NOREP within ten days after receipt, the IEP proposed in the NOREP will go into effect by default.

5. Stage five: Transition and Graduation.

- i. IDEA eligibility extends to age 21 or graduation.
- ii. Transition services are a required service to students eligible for special education under IDEA.
 1. “Transition services mean a coordinated set of activities for a student... that is designed within an outcome-oriented process that promotes movement from school to post-school activities.... Services must be based upon the individual student’s needs, taking into account the student’s preferences and interests.”¹⁸
- iii. A student entitled to special education under IDEA will graduate when he or she has met her IEP goals.
- iv. If a student accepts a high school diploma prior to age 21, the student cannot continue to receive free special education services.
- v. If a student does not graduate but turns 21 during the school term, the student can continue to receive educational services until the end of the school term.
- vi. PWN is required to parents of proposed graduation of special education student.
 1. If a parent does not agree with a LEA’s decision to graduate his child, the parent can object and request a hearing.
- vii. The extended eligibility may be used for receipt of services or therapies, remediative tutoring, technical or vocational training, or any other special education or related services the IEP team deems necessary for the student to successfully meet the goals of his IEP, including his transition goals.¹⁹

4. Transfer of Rights under IDEA

1. Under IDEA, at age 18, states may choose to transfer special education procedural and substantive rights of parents to the sole province of the student. Pennsylvania has not chosen to do so and parents retain their rights until age 21 in school matters in Pennsylvania. However, many states have chosen to transfer rights at age 18. This may be an important consideration for families considering moving out of state.²⁰

¹⁸ PaTTaN, Annotated Individualized Education Program (IEP), transition.

¹⁹ 34 CFR 300.43 (a) [20 U.S.C. 1401(34)]

²⁰ 34 C.F.R. §300.520

5. Dispute Resolution

1. The dispute resolution process, referenced above under Due Process, may be accessed by parents who disagree with the LEA over their child's needs, rights, programming, progress or any other aspect of their entitlement under IDEA or Section 504 of the Rehabilitation Act.
2. Litigation Costs: Special Education Litigation is an expert-driven area of law. Establishing parents' claim generally requires that they obtain the services of their own expert. Expert costs for litigation participation are not reimbursable to the prevailing parent, though a properly presented claim for an independent evaluation may be reimbursable.
 - i. Parents who are prevailing parties may receive attorneys fee reimbursement.

C. Autism and Aspergers

1. One in one hundred and fifty children is now diagnosed with a condition which falls²¹ within the PDD/ Autism spectrum of disorders. This growing population has placed a new and great burden on the support systems currently in place. Several of the important issues to consider:
 - a. Because of the new and developing body of knowledge concerning diagnosis and treatment of these disorders, the availability of effective and learned evaluators and providers is closely tied to local availability. There are areas of the state and the country where there are no services available, whether publicly or privately sought.
 - b. Consistency of behavioral planning is a hallmark of effective therapies. In split families with radically different parenting styles, this necessary consistency may not be available.
 - c. There is a heightened need for protection of these individuals, due to their inability to understand social cues, and the possibility of misinterpretation of their actions and affect by others. Similarly, lawyers are concerned with the interpretation of their clients' statements, affect and behaviors during interactions with the legal system.
 - i. Recently, the Superior Court of New Jersey found it to be reversible error to bar a defendant with Aspergers from presenting an expert witness for the purpose of assisting the jury in interpreting the defendant's actions and words through the prism of his disability. State of New Jersey v Franklin Jack Burr, 392 N.J. Super. 538 (2007)

Where to Find Law, Regulations and Guidance

SSI Listing of Impairments:

www.ssa.gov/disability/professional/bluebook/ChildhoodListings.htm

DPW

www.dpw.state.pa.us

²¹ US Center for Disease Control 2007 statistics.

Medical Assistance Handbook

www.dpw.state.pa.us/oimpolicymanuals/manuals/bop/ma

Pa Department of Education Guidance

Basic Education Circulars (BECs)

<http://www.pde.state.pa.us> (click on BECs under “Find Documents”)

Pa State Coordination Site for Service Information

Accessible PA <http://accessiblepa.state.pa.us>

PaTTaN (Pa DOE office of special education training and assistance, also operates the dispute resolution system)

www.pattan.k12.pa.us

U.S. Department of Education

IDEA and Implementing Regulations

<http://idea.ed.gov>

Interpretative Information: The office of the US DOE charged with implementing IDEA is the Office of Special Education and Rehabilitative Services (OSERS).

The office of the US DOE charged with implementing Section 504 of the Rehabilitation Act is the Office of Civil Rights (OCR).

Young Law Offices represents individuals and families with special needs in special education, family law, and civil rights matters. Please feel free to direct any questions to us at the email address or telephone numbers below.

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