

**SERVING THE BEST INTERESTS OF A CHILD
WITH SIGNIFICANT DEVELOPMENTAL DELAYS**
By Margaret A. Bennett

No parent wants to hear their child's pediatrician say, "Your child has significant developmental delays and may be on the spectrum." This is a frightening and challenging diagnosis for any parent. It is a known fact that parents of children with significant developmental delays such as autism are much more likely to divorce. Parents often disagree on therapies, medical treatments, medication options, behavioral plans, regular and special dietary regimes, educational curriculums, and even the day-to-day care of their child. Whether you are acting in your capacity as a mediator, guardian ad litem, a child's representative, or as an attorney representing one of the parents, it is essential to consider the additional and complex issues that should be addressed as consideration in a Memorandum of Understanding, GAL Report, Allocation Judgment or Marital Settlement Agreement.

Beginning at age 3, a child with special needs is entitled to begin an early childhood educational program through their local public school district pursuant to Public Act 94-142. Also, Public Act 99-457 provides for in-home or outpatient treatment available for a child with disabilities from ages 1 to 3 years. Prior to kindergarten, a child with developmental delays will be re-assessed, and a determination will be made whether a child will continue to receive special educational services through the public school system. If developmental delays continue through high school, the child will be entitled to attend a high school special educational program until age 22 paid for by the school district. Special educational programs are required to place a child with special needs in the least restrictive environment so that they can reach their full potential. The high school special educational

programs offer traditional educational courses but also provide life skills programs, job coaching, vocational assessment and programs to transition the child to a day program or workshop for adults with disabilities after the child attains age 22.

Parents are invited to participate and provide input in developing their child's Individual Educational Program (IEP). No less than annually, the public school will schedule a meeting that includes the members of the child's special education team. This includes the parents, and may include school social workers or psychologists, speech therapists, occupational therapists, communication therapists, the child's special education teacher and the director of the special educational program at the school. Reports are prepared summarizing the child's progress. Goals and expectations are also listed in the report and how these goals are to be implemented.

In working with parents or acting on behalf of a child with developmental delays the following should be considered when drafting the Allocation Judgment and Marital Settlement Agreement:

Special Educational Communication

A specific provision should be included in the Allocation Judgment that provides that both parents shall be allowed maximum communication with the special education team at their child's school, and each parent should be (a) notified of the IEP or 504 Plan conference; (b) permitted to attend an IEP or 504 Plan conference; and (c) notified of any changes to their child's IEP or 504 Plan. There are many educational options available for a child with developmental delays. Some school districts offer better programs than others. A provision should be included in the Allocation Judgment if the parents wish to remain in the same school district or within the same special educational cooperative that supports special

education services in multiple school districts. Often families plan to relocate to another school district; and occasionally, another state that provides better support for children with developmental delays.

Parenting Time

Parenting time can be more challenging for parents with a disabled child. Routine is very important to a child with developmental delays, especially for those on the spectrum, and parents, mediators, guardians ad litem and child's representatives should be mindful that maintaining routine is essential to the security and well-being of the child. The use of color-coded parenting time calendars, consistent house rules and disciplinary methods should be discussed with the parents. If the child is taking prescription medication, it is important that it be administered timely and that all medications be available at each home or be transferred with the child. If adaptive equipment is utilized to support the child such as electronic tablets or communication devices, they should also be transferred with the child during parenting time exchanges. Children with autism often fixate on a toy or plush animal. That item should be transferred with the child during the transition from one parent's home to the other parent's home as that item may provide a soothing effect for the child. Disciplinary practices and bedtime hours should also be consistent in both homes.

Medication and Therapeutic Programs

Often parents of an autistic child will disagree on whether their child should be on prescription medication or which medications should be administered to the child, including whether a child should be administered an antipsychotic drug or a drug with side effects. There are also some alternative therapies and treatments that parents will seek, believing that they will cure their child. It is important to include provisions that require a party to

obtain a second opinion. If possible, the parties should agree upon the child's pediatrician, therapists, psychologist and/or psychiatrist, you may wish to identify agreed upon professional in the Allocation Judgment, to avoid future disputes between parents.

Legal Guardianship

In order to avoid future acrimony, a provision should be included in the Allocation Judgment that, prior to the time the disabled child attains age 18, one or both of the parents should file a petition to establish legal guardianship of their child. Legal guardianship allows the designated guardian(s) to (a) obtain medical and other healthcare services for the child; (b) open bank accounts; (c) execute legal documents on behalf of the child; (c) obtain services for the child; (d) apply for benefits; (e) and enroll the child in educational, vocational and recreational programs. At the time of the divorce, I also suggest that the parents discuss the selection of a successor guardian. This allows for a seamless succession plan when the parents are deceased.

Supplemental Social Security Income and Home-Based Support

At age 18, a child with qualifying physical or mental disabilities is eligible for Supplemental Social Security Income (SSI) benefits unless qualifying early due to indigency. This is a monthly benefit to be paid to the disabled individual or a representative payee. Consider whether a provision should be included in the Marital Settlement Agreement that the parties will apply for SSI on behalf of their child. It is granted if the child has a qualifying disability and assets of less than \$2,000.00, excluding certain classifications of property (countable resources). If 513.5 support is being paid concurrent with SSI, it is recommended that the 513.5 support be paid into a special needs trust otherwise the SSI payments will be reduced by fifty (50%) percent for every dollar of support paid.

When a parent of a disabled child begins receiving Social Security benefits, the child becomes eligible to receive Social Security Disability Income (SSDI) benefits which are increased monetary benefits to the child and include Medicare eligibility for the child. The parents may wish to consider applying for Home-Based Support Services and other available benefits such as respite care services.

Non-Minor Child-Related Expenses

Child-related expenses are generally allocated between the parents and are included in the Marital Settlement Agreement. However, these expenses will continue beyond the disabled child's minority. Post age 26, health insurance should be considered, fortunately, many corporations allow a parent to continue to maintain a disabled child on employer sponsored health insurance plans beyond the child's 26th birthday. The allocation of out-of-pocket healthcare expenses should be included in the Marital Settlement Agreement as these expenses will also continue beyond the child's majority. The allocation of childcare costs to enable a parent to be employed should also be addressed in the Marital Settlement Agreement. The issues of special educational extracurricular activity expenses, and school and day programming expenses, should be set forth and allocated between the parties in the Marital Settlement Agreement. Park districts are required to offer special educational services to the disabled. Many park districts are part of a special educational recreational cooperative and offer a variety of services including Special Olympics programs. These programs can be as costly as \$500.00 per quarter and should be allocated between the parties.

Special Needs Trust and Life Insurance

The Marital Settlement Agreement should also require the parties to maintain their life insurance policies for the benefit of their disabled child. If the parents intend to establish

a Special Needs Trust, a provision may be included in the Marital Settlement Agreement stating whether the parties will be co-trustees; whether one parent will be the sole trustee, whether a third-party will act as trustee, or should a corporate trustee will be named in the trust document. Special Needs Trusts are required to file federal and state tax returns. The responsibility for filing the annual tax returns, including the cost of preparation and any liability due, should also be identified in the Marital Settlement Agreement. An alternative to a special needs trust is the establishment of an ABLE account pursuant to the ABLE (Achieving a Better Life Experience) Act, 15 ILCS 505/16.6. An ABLE account is an account that permits individuals with special need to save money without jeopardizing their disability benefits.

Co-parenting A child With Disabilities

It is important to facilitate opportunities for parents of children with disabilities to develop a team approach to caring for their child. No one knows what the future will hold for their child, but a child with special needs will always know when they have two loving, cooperative and supportive co- parents. On October 24, 1963, President John F Kennedy said upon signing the Maternal and Child Health and Mental Retardation Planning Act “We can say with some assurance that, although children may be the victims of faith, they will not be the victims of our neglect.” A well drafted Marital Settlement Agreement and Allocation Judgment that addresses the myriad of special needs life planning issues, which engenders parental cooperation will ensure that the child’s special needs are not neglected and the child will transition to adulthood with the love and support of both parents.

