

### **PERSPECTIVES**

on disability law



Winter 2017

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### **PARENTS & GUARDIANS ASK:**

#### "WHERE WILL MY CHILD LIVE AFTER I'M GONE?"

Of all the issues facing parents of children with significant life-long disabilities, none is more anxiety provoking than housing. "Where will my child live after I am gone?"

This is one of the most common questions we hear. It's a difficult question for parents to even ask, much less process all the answers. However, with some basic knowledge, and advance planning, this question need not be as difficult as most parents initially think.

The first step in the journey toward housing is to make sure your child is eligible for the Community Care Waiver – or at least will be eligible at some point in the future.

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to make sure your child is eligible for the Community Care Waiver – or at least will be eligible at some point in the future. The Community Care Waiver (CCW) is currently the primary funding source for the supports necessary to make housing possible. It is important for parents to understand, the CCW does not pay for the actual "bricks and mortar" of housing, but rather helps pay for the staff, supports, activities, therapies, transportation—in other words, the services the individual requires. While housing may not be cheap, it pales in comparison to the cost of services, which can mount into millions of dollars over a person's lifetime. In other words, the CCW does not pay for the place, but rather the CCW pays for what takes place. We will discuss how to pay for the actual bricks and mortar in a future newsletter.

In order to gain access to the CCW, the individual with a disability must be added to the CCW waiting list which is maintained by the Division of Developmental Disabilities (DDD). This waiting list used to be called the waiting list for "housing" or the "group home waiting list." As has always been the case, the waiting list for the CCW is extremely long. The waiting list is broken into two broad categories: "Priority" and "General." The Priority category is the only part of the list that moves and it can take 12 or more years to reach the top. Therefore, advance planning is key. We have helped hundreds of families to navigate these lists. It is important to remember, the sooner your child's name is added to the list, the sooner you will have options for housing.

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# "WHERE WILL MY CHILD LIVE?" continued

Next, parents should add their name to their county Section 8 voucher waiting list. These lists vary from county to county, but make no mistake, all are very long. In addition, DDD currently provides access to a number of "state vouchers." Although access to state vouchers appears to be somewhat unclear as DDD has failed to publish rules and regulations on this issue, it appears access to state vouchers may be tied to reaching the top of the CCW waiting list or being determined an emergency.

However, once access to CCW supports are obtained, a variety of housing options are available. Parents may still access traditional group homes, or supervised or supported apartments which are typically operated by various non-profit provider agencies. However, more and more families are choosing to create their own housing options. Some families may purchase a condo or a small home, thereby providing the home while utilizing CCW inhome supports to pay for staff and activities. In still other instances, parents are pooling their resources and purchasing property suitable for a number of adults with disabilities such as a four or five bedroom home. Another option is to purchase property and either donate or rent the real estate to a non-profit provider to operate and manage.

Each of these options come with opportunity and risk. No one option is right for every family. For those who chose to purchase or rent a home for their child, careful consideration should be given to whether the real estate should be owned by a trust, a non-profit entity, or a limited liability corporation (LLC). Careful planning is needed in these instances. The legal obligations and benefits will need to be thoroughly explored.

Nevertheless, despite that this may seem to be an impossible task, it is really nothing more than a long journey. It is never too early to start planning and laying the groundwork for future housing options.

# BULLYING AND SPECIAL NEEDS STUDENTS IN NEW JERSEY

New Jersey has what is considered to be one of the toughest laws against bullying in the country. The statute covers not only incidents which take place in the classroom, but also incidents that occur outside of school and even online.

Bullying is generally defined as any communication, gesture, or act which is "reasonably perceived" as being motivated by a "distinguishing characteristic" and which substantially disrupts or interferes with the orderly operation of the school or the rights of students, and that a reasonable person would know would be harmful to another person. The statute specifically prohibits students from being targeted based on a mental, physical, or sensory disability. However, the statute has a very broad impact and has been found to apply to any "distinguishing characteristic" including harassing a student for having head lice, and making fun of a student for being vegetarian.

New Jersey's statute creates a detailed procedure for how a school district must deal with alleged bullying incidents. All possible bullying incidents must be reported to the principal on the day that they occur, and the principal must inform all parents/guardians of all students involved in the purported incident. Within one school day, an investigation into the incident must begin. This investigation is conducted by the school's designated anti-bullying specialist, and must be completed within 10 days of the incident. The superintendent must then receive the report within two days of completion and can then take appropriate action (discipline, counseling, training, etc.).

If the parent of a student involved in an incident disagrees with the report or the superintendent's actions, the parent is entitled to information about the investigation and may request a hearing with the school board in its executive session. The board may also hear from the anti-bullying specialist at the hearing. At its next meeting, the board must issue a written decision affirming, rejecting, or modifying the superintendent's decision. The board's decision may be appealed to the commissioner of education. Merely following the procedure described above does not insulate the school from liability; the school must take appropriate actions that are reasonably calculated to end the bullying.

If your child is being subjected to bullying, we recommend that you report each incident to school administrators as soon as possible. If the school does not remedy the situation within a reasonable time period, a formal complaint against the school may be filed under the statute. Additionally, it is important to remember that repeated bullying may have a devastating effect on a student's ability to learn. Students with disabilities are a particularly vulnerable population, and repeated bullying without intervention could lead to a denial of a free, appropriate, public education under the Individuals with Disabilities Education Act, and may also constitute a violation of several other state and federal laws protecting individuals with disabilities.

It is also important to remember that students with disabilities may not only be the victims but also the perpetrators of bullying incidents. If your child's behavior is characterized as bullying, but is really driven by his or her disability, this may be inappropriate. When substantial disciplinary action is taken against a student with a disability, it should be determined whether that student's actions were a manifestation of the student's disability. If they were, steps should be taken by the school to address the behavior in the student's IEP.

### **COMMUNITY CONNECTIONS**

In addition to donating time to local groups and organizations throughout New Jersey and Pennsylvania, Hinkle, Fingles, Prior & Fischer works with and supports several statewide not-for-profit organizations.



Visit our Facebook page for more info on our work in the community.

















### **LEGAL VICTORIES**

#### **Hospice Care in DDD Residential Settings**

Hinkle, Fingles, Prior & Fischer represented the siblings and legal guardians of a 66-year-old woman, who in addition to having developmental disabilities, is legally blind and terminally ill with cancer. She has lived in the same group home for nearly 30 years and despite her condition is able to recognize and interact with her family, house mates, group home staff, and other caregivers and she derives great joy from being with familiar people in the comfort of her home.

Without any input from her doctors, her guardians, or DDD, the group home was planning to bar a dying resident from returning to her home (the only home she has known for the last 30 years), just two days before Christmas, and with only two days' notice given to her family.

Her doctors recommended she receive in-home hospice care. Despite the advice from her doctors, the provider agency operating the group home unilaterally, and in violation of the law, decided it would not permit hospice care in the group home. Most egregiously, while she was in the hospital having a routine procedure, the group home operator advised the family she would not be allowed to return to her home on December 23, 2016, her scheduled discharge date.

In other words, without any input from her doctors, her

guardians, or DDD, the group home was planning to bar a dying resident from returning to her home (the only home she has known for the last 30 years) just two days before Christmas, and with only two days' notice given to her family.

Her guardians, distraught, came to Hinkle, Fingles, Prior & Fischer for assistance. HFPF successfully obtained an emergency injunction from the Court late in the day on Friday, December 23rd. The Court Ordered her return to the comfort of her home, where she would continue to live and receive appropriate care, including hospice care. Thanks to the fast action of her family and the swift legal advocacy of HFPF, she was able to spend Christmas at home surrounded by her family and friends. Additionally, her guardians can have peace of mind knowing that they will have input into the decisions regarding her care and placement, and that she will only be moved to a new placement if it is in her best interest. This is in accordance with long-standing law and with the protection of the Court's Order.

### Eligibility for NJ Division of Developmental Disabilities Services

In recent years, we have seen DDD inappropriately deny applications for eligibility. In the overwhelming number of appeals handled by this firm, DDD's initial decision is reversed by a Judge. When families are trying to decide whether to appeal a denial by DDD, they should remember that a successful appeal opens the door to potentially millions of dollars' worth of services over the course of one's lifetime. Experienced and skilled representation and knowledgeable experts are essential to a successful appeal. In 2016, Hinkle, Fingles, Prior & Fischer successfully represented a number of families appealing a denial of eligibility for DDD services. Two cases which went to a hearing demonstrate a number of trends coming out of DDD.

In one case, the firm represented a 20-year-old woman with autism. After a two-day hearing the judge assigned to the case reversed DDD's denial and Ordered DDD to find her eligible for services.

One of the primary issues in this case is whether the person with a disability has autism (a developmental disability) or bi-polar disorder (a mental illness). The young woman with a disability had been diagnosed with childhood bi-polar disorder (a diagnosis largely discredited today). Despite the fact several different treating and evaluating professionals over the years diagnosed her with autism, DDD's internal psychologist refused to acknowledge the applicant has autism and stubbornly insisted she was mentally ill. In effect, DDD cherry-picked

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the diagnosis and records that suit it best and simply refused to concede she has autism. In the end, the Judge did not find DDD's witness credible and did not accept DDD's testimony.

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#### INCOME TAXATION OF SPECIAL NEEDS TRUSTS

# Accommodating Students with Food Allergies and Chemical Sensitivities

Trustees of special needs trusts are responsible to make sure that both Federal and State income taxes are paid by the trust each year. This article will focus on Federal income tax returns. Generally speaking, trusts are treated as separate taxable entities, which means that a separate tax return must be filed. Special care must be taken when filing taxes because the two main kinds of special needs trusts are treated differently.

#### **1ST-PARTY SPECIAL NEEDS TRUSTS:**

1st-party special needs trusts are also referred to as "payback" trusts, "d(4)(A)" trusts, and "OBRA" trusts. These trusts are funded with assets that belong to the individual with a disability, usually from the settlement of a lawsuit or child support payments. For tax purposes these trusts are treated as "grantor" trusts, which means all of the income to the trust is actually taxable to the beneficiary of the trust. In most cases the Trust will have its own taxpayer identification number (called "TIN number" or "EIN number"), so a Form 1099 will be issued to document "miscellaneous income." At that point the Trustee can file an informational Form 1041 for the trust beneficiary with a letter attached explaining the grantor status of the trust. For 1stparty trusts that use the beneficiary's social security number, no separate informational Form 1041 needs to be filed. In any case, any tax owed in a given year may typically be paid from the trust, even though the tax is theoretically owed by the beneficiary.

#### **3RD-PARTY SPECIAL NEEDS TRUSTS:**

3rd-party special needs trusts are trusts which are funded with assets that belong to individuals other

than the person with a disability. Usually these trusts are created as part of a parent's estate plan, and funded through a parent's Will. For tax purposes a 3rd-party trust is not treated as a "grantor trust" but rather as either a "qualified disability trust" or a "complex trust." When properly drafted, a 3rd-party special needs trust can usually be classified as a "qualified disability trust" which is beneficial because those trusts are entitled to a tax deduction equivalent to the standard personal deduction. Either way, the trustee must ensure that a Form 1041 is prepared and filed for the trust and that any taxes owed are paid.

Due to the relative complexity of tax reporting, we recommend a trustee have the taxes prepared by a tax professional. The cost of tax preparation may be paid for out of the trust itself. Trustees should also remember many other taxes may impact the trust including gift taxes, capital gains taxes, estate taxes, etc. This is another reason why hiring a professional can be beneficial.

It is also important to remember there is a difference between the definition of "income" for income tax purposes and the definition of "income" for Social Security and Medicaid purposes. If your tax preparer tells you the income from the trust is attributable to your child, do not panic and think your child is at risk of losing his or her Social Security and Medicaid benefits. So long as the trust did not make payments to your child which will be considered income by Social Security, your child can have an unlimited amount of income for tax purposes and still be eligible for means-tested government benefits.

Students are being diagnosed with food allergies and chemical sensitivities at a higher rate than ever before. For example, the number of students under the age of five with severe peanut allergies has doubled during the past ten years.

Because students spend such a significant portion of their days in school, it is essential that schools be equipped to accommodate the needs of students with food allergies and chemical sensitivities.

Students with food allergies and chemical sensitivities are entitled to accommodations in school pursuant to a number of laws, the most significant of which is Section 504 of the Rehabilitation Act of 1973. Among other things, Section 504 prohibits discrimination against students with disabilities in the school setting. By and large, students with severe food allergies or chemical sensitivities will fall within the protections of Section 504.

Section 504 requires that school districts modify policies, practices, and procedures to ensure students with disabilities are not excluded from the educational system or denied equivalent opportunities to benefit from their educations as non-disabled students. In the absence of appropriate accommodations, students with severe food allergies or chemical sensitivities may suffer educational harm by being unable to attend all or part of the school day due to the presence of allergens or other irritants in the school environment. In other cases, such students may be unable to benefit from their educational experience because of the symptoms they experience in the presence of allergens or irritants.

The types of accommodations that may be necessary depend upon the unique needs of the student.

Accommodations that have been found necessary in prior cases have included evaluation of the school environment by a specialist; the use of portable air filters; bans on other students' and staff introduction of allergens or irritants into the school or classroom environment, such as the imposition of a ban on the wearing of perfumes and fragrances; requiring all staff who come in contact with a student to be proficient in the application of an Epi-Pen or similar device to mitigate students'

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#### **LEGAL VICTORIES** continued

In a second case, DDD determined a 26-year-old man with Asperger's syndrome ineligible for services. After a one-day hearing the judge assigned to the case reversed DDD's denial and Ordered DDD to find him eligible.

DDD's expert determined him ineligible, in large part, due to his superior IQ and therefore argued he had potential to be successful. In its quest to find him ineligible DDD ignored his inability to manage his self-care needs, to cook, do laundry, shop, manage money, and to obtain and maintain employment even with the assistance of a job coach. Instead, DDD focused on the fact that someone with his potential should be able to care for himself, live independently and financially support himself. In effect DDD ignored its own eligibility criteria.

In both of these cases, the families knew DDD's determination could not be correct and were willing, with the legal advocacy of HFPF, to challenge DDD to ensure services for their family member for years to come.

#### **ALLERGIES** continued

reactions to allergens or irritants; and the designation of a "clean room" to which the student may retreat in the event that an allergen or irritant is introduced into the school environment.

Some schools have responded to the needs of students with severe food allergies or chemical sensitivities by designating particular areas within the school that will be, for example, "peanut free" or "fragrance free." While such an approach may work in some cases, it often does not. For example, a student from a different class may unintentionally introduce peanut particles into common areas such as the cafeteria or gymnasium. No matter how minute, these particles may be sufficient to provoke a potentially life-threatening reaction in a student with a severe peanut allergy.

Consequently, on an increasing basis, school districts are being required by courts and regulatory agencies to impose school-wide bans on allergens or irritants if such a step is necessary for the student with the allergy or sensitivity to attend school and derive full benefit from his or her school experience.