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**VIDEO - "How To Obtain Funding / Services For Developmentally Disabled Children & Adults In The State Of Illinois"**

This video is to help you understand what needs to be done by a parent or caregiver of either a developmentally disabled child or adult in the State of Illinois in order to obtain services.

- \* Do you know why it is essential to get your child's name on State of Illinois "Waiting List" for services ?
- \* Do you know that if your child is between the ages of 3 - 22, he or she can receive from the State of Illinois approximately \$1,350 per month for supports and services ?
- \* Do you know why your child should not have more than \$2,000 in assets ?
- \* Do you know that when your child turns 18 years or age, he or she may be entitled to receive approximately \$674 per month in SSI payments ?
- \* Do you know that as a result of a lawsuit settled in Illinois, thousands of developmentally disabled adults are entitled to community based funding ?
- \* And, do you know that with proper estate planning, parents and relatives can leave money to the disabled child through a Special Needs Trust and the monies in this type of trust will not financially disqualify he disabled person for funding for government services and benefits ?

Before I answers these questions, I will introduce myself to you, so you can understand why I am telling you that your developmentally disabled child is entitled to all the services which he or she needs under the law.

I am Robert Farley, an attorney who has been practicing law for approximately 30 years.

I am also, the father of a developmentally disabled son, Ryan, who is 24 years old, who is autistic and functions at a mental age of approximately 1 ½ to 2 ½ years. Ryan needs intensive staffing and close supervision. Today, Ryan lives in a group home with 5 other developmentally disabled persons and attends a day program. Ryan is entitled to these services under federal law because he is developmentally disabled. Ryan's every need is met in this program and he is basically set for life. The cost of the program is approximately \$150,000, which is a federal medicaid program, with ½ being paid by the federal government and ½ being paid by the State. It was not easy to get Ryan what he was entitled to under the law, so I want to inform you of your rights so you to can succeed on behalf of your child.

I graduated from Northwestern University School of Law.

I have argued cases before the Illinois Supreme Court; before the United States District Courts; and the United States Court of Appeals.

I have filed lawsuits against the State of Illinois on behalf of disabled persons to obtain community based services after the State had previously denied funding.

In one case, the United States Department of Justice filed a legal brief to support the claim which I raised that developmentally disabled persons can sue the State of Illinois under the Americans for Disability Act to receive community based services.

Simply put, I have successfully represented children and adults with developmental disabilities in obtaining the appropriate community based services.

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If you want a written transcript of this video, then go to my website at [www.farley1.com](http://www.farley1.com) and click on the "Publications" section.

If you want to receive a free e-mail monthly newsletter on disability issues affecting Illinois, you can go to the website and subscribe.

I am available to speak to parents, groups and agencies on disability issues.

## **The State of Illinois “Waiting List.”**

One of the first things that a parent must do, is get their child on the State of Illinois “Waiting List” for Services. The “Waiting List” is also referred to as “PUNS,” P-U-N-S which stands for “Prioritization of Urgency of Need for Services.” The PUNS or the Waiting List was first set up by the State in 2004.

To get funding for services, the disabled child or adult must be on the list. The State of Illinois has stated that one of the factors for families getting funding for services is “length of time on the [PUNS] database.

To get on the “Waiting List” you need to contact your local Pre-Admission Screening Agency or PAS Agency and they are also known as Independent Service Coordination Agencies. Each PAS Agency serves a specific geographical area in the State, and you can find the name and phone number of your agency by going to the “Publications” section on my web page.

What happens after you are on the Waiting List and your child needs services now and their name has not been selected by the State ?

I WILL ANSWER THAT QUESTION SHORTLY.

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## **The State Of Illinois Children’s Program For Developmentally Disabled Persons.**

There is a new program which began in July, 2007 in Illinois for children who are developmentally disabled and are between the ages of 3 - 22. This program allows families to obtain services and supports over and above what your child receives in special education. This particular government. program does not consider the financial status of either the parents or child.

A child in this program can receive approximately \$1,350 per month for supports and services, which can include, personal support for the child. Personal support means that you can hire someone who is at least 18 years of age to watch or assist in the care of your child. A parent cannot be paid in the children’s program to take care of their own child, but an adult brother or sister or relative or grandparent could be paid.

Funding in this program can be used for to pay for occupational, physical and behavioral therapy.

Funding in the amount of \$15,000 - - over and above the monthly rate of \$1,350, can be used for: assistive technology; adaptive equipment; vehicle modifications; and home accessibility modifications. For example, an autistic child may need a fence to be installed in their backyard to prevent him or her from running away.

**WHY does this children's program exists in Illinois for children ?**

The reason this program exists is because federal law requires Illinois to provide disabled person access to services and supports in the community and not in an institution.

AS Parents or Caregivers, you need to understand that under the law, before the passage of the ADA or the Americans with Disability Act, developmentally disabled children and adults were entitled to live in an Institution. However, parents don't want to send their child or adult child to live in institutions but rather, want them to remain in the community.

The **Americans with Disability Act**, a federal law, requires the States, including Illinois to make modifications to their institutional programs to provide disabled persons services in the community. Accordingly, this new children's program allows services to be provided in the community.

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**Why Should A Child Have No More Than \$2,000 ?**

The reason parents are generally told not to have more than \$2,000 in the developmentally disabled person's name is due to the fact that many government programs for the disabled have financial eligibility requirements.

For example, at the age of 18, a disabled person will be entitled to SSI (Supplemental Security Income) in the approximate amount of \$674 per month if he or she has less than \$2,000 in their name or in any custodial accounts. At age 18, the government does not look at the income or assets of the parents because the disabled person is an adult.

However, if the disabled person has more than \$2,000 in assets, then I can set up a Special Needs Trust and their money can be transferred now into the Trust and he or she can then qualify for benefits.

Even if the child has less than \$2,000 in their own names, Parents should consider establishing a Special Needs Trust for their disabled child, because if your child inherits money from you or grandparents or relatives, then those monies may have to be exhausted before qualifying for benefits.

In a Special Needs Trust, your child will be the beneficiary of the Trust and the funds in the trust can exceed \$2,000 and those monies will not disqualify him or her from obtaining funding or benefits.

With a Special Needs Trust, your Will would not give money directly to the child would give the money to the Special Needs Trust.

The beneficiary on your life insurance policy would not list the disabled child as that would pay money directly to the child and bypass the Special Needs Trust.

If grandparents or relatives want to leave money to your child, they do not have to create a Special Needs Trust, if you have already created one for your child. Then, they can leave money to the Special Needs Trust and not to the child.

It is very important that the attorney who drafts the "Special Needs Trust" has experience in the area and does not draft the typical Trust which many families use in their estate planning.

You can call me or e-mail me to discuss setting up a Special Needs Trust.

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#### **Adult Home Base Services.**

An adult with developmental disabilities at age 18, like the children's program, can receive funding for in-home supports and services.

If the 18 year old is still receiving special education, then the amount of funding is the same as the children's program which is approx. \$1,350 per month.

When the disabled person exits the special education program, the amount of funding increases to approximately \$2,000 per month.

The funding can be used for a day program, it can be used for personal support of the disabled person. Unlike the children's program, a parent can be paid to take care of their own child.

Additionally, the \$15,000 funding for technology, equipment and home and vehicle modifications is also available.

The reason the Adult Home Base exists in Illinois is for the same reasons that the children's program exists. Federal law, the ADA, requires Illinois to provide community based services to disabled persons.

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### **Litigation For Community Based Funding / Services.**

In the year 2000, I filed a federal lawsuit against the State of Illinois on behalf of a number of families who were unable to obtain community based residential and in home support services for their children. The State claimed that they had no legal obligation to provide community based services to the disabled. The State claimed that it did not have to provide funding to persons who they did not consider to be an emergency or priority.

After the Federal United States Court of Appeals held that my clients, developmentally disabled persons were entitled to sue the State of Illinois for violating the Americans with Disability Act by failing to provide community based services, Illinois settled the case and every family received funding for community based services.

Recently, another case has settled in Illinois which will provide community based funding for thousands of developmentally disabled persons over the next 6 years.

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**NOW**, I have just told you about all these wonderful programs in Illinois for the developmentally disabled and now you have your name on the Waiting List and you need services now and your name has not been selected. What do you do ?

**FIRST**, you must have the **MINDSET** that **your child is entitled to funding as a matter of law** and the words “**NO FUNDING**” or “**YOU MUST WAIT**” are not acceptable. Federal law requires that you receive funding with reasonable promptness and some courts have stated that reasonable promptness must be within 90 days after applying.

**Remember**, Illinois is currently **ranked 51<sup>st</sup>** in the United States in serving people with developmental disabilities in small community based settings. (The reason Illinois is 51<sup>st</sup>, when there are only 50 States is because the District of Columbia is included in this ranking)

If the **State of Illinois** says that you cannot get funding, do you want to accept the denial at face value and accept the status quo from someone who is ranked 51st ?

**In my opinion**, one of the reasons Illinois is ranked last is due in part to its failure to comply with the **Americans with Disability Act**.

**Now, If you can get funding for services within a reasonable time frame**, then the system works for you.

**HOWEVER, if you cannot get funding for services, then the system has failed your child.** You have not personally failed, but Illinois has failed your child.

**So, if Illinois tells you** any of the following reasons why you cannot get funding, then please call me.

- - Illinois may tell you that you cannot get services until we **pull your name** from the PUNS or Waiting List, so don't call us, we will call you. If you need services now and have been waiting more than 90 days to get funding, then please call me.

- - Illinois may tell you that there are **many people ahead** of you on the Waiting List **or** that there are **more people deserving** than your child. **The fact that people have been waiting for years, does not justify violating federal law. Don't accept no. Sometimes the squeaky wheel gets services, especially in Illinois.**

- - Even if you do get funding, there may come a time when your child needs more funding to meet his or her unique needs. If Illinois say that the program does not permit more funding, then federal law may require Illinois to modify their program to provide increased funding to your child.

**Finally**, from my years of experience, to get something good and appropriate for your child in Illinois, may not come easy. However, when you do succeed and when the system works for your child, then hopefully the future will be as promising for your child as it is for mine.

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Thank You for your time.