New Edition
2021

# “The Book”

## How To Navigate
## The Illinois Disability System

What Every Parent and Educator Needs to Know About Obtaining Funding and Services for a Disabled Child/Adult in the State of Illinois...

***...and How to Secure Their Future***

*by Attorney Robert H. Farley, Jr.*

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# What Every Parent and Educator Needs to Know About Obtaining Funding and Services for a Disabled Child/Adult in the State of Illinois and How to Secure Their Future

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This Book & My Life are Dedicated to Ryan Farley,
My Disabled Son and to Your Disabled Children

This book can be copied and distributed to parents and all concerned persons who believe that a disabled person is entitled to a life which addresses all their needs.

## January – 2021

## Index

## Entitlement to Disability Services

Securing services for children and adults with disabilities can be one of the most challenging experiences family members and guardians face as they care for their loved ones. Effective advocacy is critical as they work to maximize the benefit of public services and entitlements, and protect their assets.

Be aware that many so called "experts" will tell you that your son, daughter or family member is not entitled to disability funding or services and that he or she does not meet the criteria to obtain funding.

Disability funding and services are available for persons who are developmentally disabled, mentally ill, physically disabled, elderly or medically fragile.

During the last 10 years, Attorney Robert H. Farley, Jr. has filed 7 Federal Class Action Lawsuits against the State of Illinois which has successfully resulted in changing the disability system in Illinois to provide Millions, Hundreds of Millions, and Billions of dollars for disability services. No other attorney in the United States has achieved this recent success.

If any person tells you that your family member cannot obtain services, then you may contact Attorney Robert H. Farley, Jr. by email (farleylaw@aol.com) or phone (630-369-0103) to discuss your particular situation and there is no charge for this initial email or phone contact.

Mr. Farley's comprehensive experience in the disability field is set forth at the end of this book.

# Overview of Illinois Disability System

In Illinois, there is no single point of entry to obtain disability funding and services. Please refer to the following disability programs in order to begin the process to secure the services.

# *Developmental Disability Services*

## State Of Illinois “Waiting List” or “Puns List”

1. **Get your child’s name on the State of Illinois “Waiting List” for services immediately.** Your child cannot get services unless he or she is on the list. The State of Illinois wrote on January 4, 2008 that one of the factors for families getting funding for services is “length of time on the [PUNS] database.” The Waiting List is formally called PUNS - “Prioritization of Urgency of Need for Services.”

**Contact your local Independent Service Coordination Agency to get on “Waiting List.”**

| | |
|---|---|
| ■ DuPage, Kane, Kendall County – *Service, Inc.* | 630-425-2350 |
| ■ Will, Kankakee, Grundy County – *Service, Inc.* | 815-741-0800 |
| ■ McHenry County – *Service, Inc. of Illinoi* | 815-477-4720 |
| ■ Cook (Northern) – *Community Alternatives Unlimited* (Chicago-North; Lake County) | 773-867-4000 |
| ■ Cook (Southern) – *Suburban Access* | 708-799-9190 |
| ■ Cook (City of Chicago - South) – *Community Services Options* | 773-471-4700 |

*(For a List of All Agencies – See Exhibit “A” – Map and Offices)*

2. **State of Illinois will not pull your child’s name off the “Waiting List” if your child is classified as “Planning for Services.”** You want your child to be classified as **“Seeking Services.”** As the result of a settlement of Class Action Lawsuit the State of Illinois is required to provide funding/services for developmentally disabled persons 18 years or older. The State of Illinois will annually pull over 600 adults from the Waiting List. It is expected that for future years, the number pulled will increase as the lawsuit mandates that the Waitin List move at a reasonable pace. Only those persons classified as “Seeking Services” will be pulled as the result of the court settlement.

**There are 2 different categories on the “PUNS” List.**

- Seeking Services – needs services within one year..
- Planning for Services – not actively seeking services at this time; does not need services for at least a year.

*(See the pages from the “PUNS Manual” for examples of “Seeking Services” – See Exhibit B)*

3. **What if you cannot wait for your name to be pulled off the “Waiting List” and you need immediate funding now.** For every disabled adult (18 years or older) who is in “Crisis,” they are entitled to immediate funding under a Federal Court Order, even if they were not pulled from

the Waiting List. There are 5 categories of Crisis Criteria for a disabled adult (18 years or older). If your child satisfies 1 of the 5 categories, then he or she is entitled to immediate funding. The failure to fund a person in "Crisis" is a violation of a Federal Court Order. If your child is denied funding, then you should contact Attorney Robert H. Farley, Jr.

### The 5 Categories of Crisis Criteria (18 years or older)

A. **The Individual's caregiver is unable to address the support needs of the Individual, thereby jeopardizing the Individual's health, well-being, and/or safety;**
B. The Individual's behaviors (e.g., verbal and/or physical aggression, bodily harm to self and / or others) put the Individual and/or family member(s) at risk of serious harm;
C. The Individual's caregiver(s) are deceased;
D. Physical and/or mental injury and/or sexual abuse is being inflicted on the Individual;
E. The Individual is homeless or without domicile.

*(See Exhibit C which lists the Adult Crisis Criteria as the result of a Federal Court Order.)*

*(See Exhibit D which provides examples of the Crisis Criteria for Adults)*

### Crisis Criteria for Children (younger than 18 years)

A. The caregiver is unable to keep the child safe;
B. **The caregiver is unable to meet the child's support needs.**
The family dynamics (e.g., multiple children with disabilities dependent upon the caregiver) as correlated with the medical, physical, and/or behavioral needs of the child place demands on the family that put the child and/or family member(s) at serious risk;
C. The child's behaviors (e.g., verbal and/or physical aggression, bodily harm to self and/or others) put the child and/or family member(s) at risk of serious harm.

*(See Exhibit E which provides examples of the Child Crisis Criteria)*

4. **Now that the parent recognizes that the developmentally disabled person is in "Crisis," what are the necessary steps for the parent to request immediate funding?** Attorney Robert H. Farley, Jr. recommends the following steps which have been successfully used:

A. Write a letter, approximately one and one half pages, setting forth the reasons why your child is in "Crisis." You can forward the letter to Mr. Farley and he will proof it for you at no cost to you.
B. After you have set forth the reasons why your child is in "Crisis", then you need

to contact your local service coordination agency and tell them that you cannot wait for your child's name to be pulled from the waiting list. You tell them that they need to submit a formal application to the State of Illinois to request funding for your child as a "Crisis."

C. If you have any questions regarding these procedures, you may contact Mr. Farley, at no cost to you.

## 5. The types of disability funding a developmentally disabled person can receive from the State of Illinois.

**A. Group Home/Residential Funding.** Funding to reside in a community based residential setting is commonly referred to as a "CILA" which means a Community Integrated Living Arrangement.

**B. Home-Base Support Services.** When a disabled person receives funding from the State of Illinois for Home-Base Support Services, the amount of funding is approximately $1,540 per month. When the disabled person exits special education, the amount is approximately $2,300 per month. The parent does not get a check from the State of Illinois, but gets to use services up to the designated amount. For example, a personal attendant or job coach can be paid by the State from the funds. A day program can be utilized with the funding. Listed below is a partial list of how the funds can be used. For further information, please contact your local Service Coordination Agency.

**Children's Services Funding** - including but not limited to, personal support; respite; behavior intervention; therapies; modifications for home, vehicle and adaptive equipment.
*Note: This Medicaid Program for Children waives family income, so the income of the family will not prevent a child from qualifying for Medicaid and receiving these services.*

**Adult Services Funding** - including but not limited to, personal support; day programming services; respite; behavior intervention; therapies; transportation; and modifications for home, vehicle and adaptive equipment.
*Note: When a disabled person attains the age of 18, he or she is considered an adult and family income will not prevent funding for services. So long as the disabled person, 18+, has less than $2,000 in his or her name, then the person will qualify for Medicaid which provides the funding for this program.*

# State of Illinois Definition of a Development Disability

There are 2 different ways a person will be considered "Developmentally Disabled" in the State of Illinois.  The first way to satisfy the definition is for a person to have an IQ of 70 or below and the disability occurred before the age of 22 years.

The second way for a person to be considered "Developmentally Disabled" would be if <u>all</u> of the following conditions are substantiated by an appropriate professional:

1. It is attributable to Cerebral Palsy, Epilepsy, Autism, or any other condition, other than mental illness or infirmities of aging, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services similar to those required for these persons.
2. It is manifested before the individual reaches age 22.
3. It is likely to continue indefinitely.
4. It results in substantial functional limitations in three or more of the following areas of major life activity:
    a) Self-care;
    b) Language;
    c) Learning;
    d) Mobility;
    e) Self-Direction; and/or
    f) Capacity for Independent Living.

# Estate Planning for Families with a Disabled Child

## SPECIAL NEEDS TRUSTS

Parents of a disabled child should establish a "Special Needs Trust" to benefit the child. A "Special Needs Trust" allows the parents or anyone to direct money to the trust so that the funds can be used by the Trustee(s) to benefit the disabled person without making him or her ineligible for the receipt of governmental benefits based on need such as Supplemental Security Income (SSI), Medicaid and its medical benefits. Without a "Special Needs Trust" the disabled person may be required to exhaust almost his or her inheritance before becoming eligible for government benefits or the funds may be required to be paid over to the government as reimbursement for care and expenses of the disabled person.

The funds in the "Special Needs Trust" can be used to supplement and not supplant government benefits. The purpose of the "Special Needs Trust" is to avoid the disabled person from being disqualified from receiving government benefits and to maximize financial resources to ultimately provide him or her with the best quality of life due to their disability. 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.

For example, a person who is seeking funding for developmentally disabled adult services, cannot have more than $2,000 in their own name. Likewise, a person applying for SSI benefits at the age of 18 or older, cannot have more than $2,000 in their own name. By transferring excess monies into a Special Needs Trust, the disabled person is able to qualify for government benefits and services. There are two types of Special Needs Trust and the selection of one or both Trusts will depend upon either the disabled person's financial situation or the family's financial situation.

By creating a Special Needs Trust now, a relative or friend can either gift monies to your child's Special Needs Trust or leave a portion of their inheritance directly to the Special Needs Trust. The relative or friend does not need to create a Special Needs Trust, if you have already created the Special Needs Trust. All that the relative or friends need to do is name the Special Needs Trust as a beneficiary or designate that a specific sum of money or a portion of their estate be distributed to the Special Needs Trust. You do not want the relative or friend to distribute monies directly to your child as it would impact government benefits and services.

Accordingly, your Will would not give money directly to your disabled child but would give the money to the "Special Needs Trust." Likewise, the beneficiary for life insurance policies and retirement funds would not be the disabled child, but would be the "Special Needs Trust," so that the monies would flow to the Special Needs Trust.

It is very important that the attorney who drafts the Special Needs Trust has specific experience in the area and does not draft the typical Trust which families generally use in their estate planning. If not structured properly, the individual's assets may render them ineligible for SSI or Medicaid and could lead to government agencies seeking judgments against parents and guardians for the past costs of publicly financed health care and cash benefits.

Attorney Robert H. Farley, Jr. has specialized experience planning and developing Special Needs Trusts to protect assets and improve the quality of life of individuals with disabilities.

## ABLE Account

An ABLE Account is not a substitute for a Parent setting up a Special Needs Trust. An ABLE account has a Payback feature which means that upon the passing of the disabled person, before any monies in the account would be paid to the designated beneficiaries on the account, Medicaid would be entitled to be reimbursed for any monies which they paid during the lifetime of the disabled person. If a parent or relative wanted to contribute their own money to benefit the disabled person, then a Special Needs Trust should be set up and there would be no Payback requirement.

An ABLE Account would be appropriate for the disabled person to put his or her own money into this account as these monies will not count towards the $2,000 limit on assets which a disabled person must have in order to qualify for SSI and Medicaid. A disabled person can have up to $100,000 in their ABLE Account and still qualify for SSI.

Mr. Farley is available to meet with you and discuss the appropriate Estate Plan for your disabled child in order to maximize government benefits for your child and discuss upfront what would be the legal fees for the Estate Plan / Special Needs Trust.

## SSI Benefits for Disabled Adults (18+)

### SUPPLEMENTAL SECURITY INCOME (SSI)

SSI is a federally financed and administered, needs-based program, which guarantees a national minimum income level for the aged, blind, and disabled with limited income and resources.

Every disabled person should apply for SSI when they turn 18 years of age. Most 18 year old developmentally disabled persons will satisfy the tests for limited and income and resources. Because the developmentally disabled person is an adult (18 +), the income and resources of his or her parents are not considered. Eligibility for SSI will be based on the income and resources of the developmentally disabled person.

### Frequently Asked Questions:

**Q. How much will the developmentally disabled adult receive in SSI benefits?**

A. Effective January 2020, the maximum SSI payment for an eligible individual is $783 per month.

**Q. Why do some developmentally disabled persons receive approximately 1/3rd less than the maximum SSI payment?**

A. If your child lives rent free in your home, then the SSI payment will be reduced by1/3rd. The current living arrangements of the developmentally disabled person will be a factor in determining the amount of his or her SSI monthly payment. The developmentally disabled person can get up to the maximum payment if he or she is living in someone else's household (i.e., parents) as long as he or she pays for his or her food and shelter costs. If the developmentally disabled person is living in someone else's household and does not pay his or her food and shelter costs or pays only part of their food and shelter costs, then the SSI monthly benefit may be reduced up to 1/3rd the maximum amount.

There are 2 different ways ("Fair Share" or "Rent as a Tenant") to get the full amount of SSI benefits and you need to understand both approaches. My experience is that in most situations, the amount of "fair share" exceeds the SSI payment and accordingly will not work and the "rent" approach is the preferred manner.

**FAIR SHARE**: To determine whether or not you are paying your fair share of your household's expenses, SSI officials will require you to itemize your household's expenses and divide those expenses by the number of people living in the home. Household expenses include total monthly expenditures for food, rent, mortgage, property taxes, heating fuel, gas, electricity, water, sewerage and garbage collection. If the amount of expenses divided by the number of people in the home is less than an amount you are capable of paying from your own income, SSI will allow you to keep your whole SSI check. If the amount is greater than the amount you receive in earnings and SSI benefits (even if only over by a few dollars), SSI will deem this excess amount as a voluntary contribution toward your support, and will reduce the SSI check by 1/3rd.

**RENT AS A TENANT**: You will need to charge rent to your child in an amount which you would charge anyone else for renting a room in your house. For example, if the going rate to rent a room in your neighborhood is $350 per month, then you charge your child $350 per month. Your child is a separate household living in your household. You do not provide free food to your child as he or she is responsible to pay their rent and pay for their food.

Sometimes a parent asks, "How can you charge rent if the person has no money?" One way to answer that question is that the child owes you.

If your child is currently receiving SSI with a 1/3rd reduction, you can always contact Social Security and inform them that there has been a change in circumstances and that you are now charging your child rent.

**Q. What 'resources' or assets can a disabled person have and still qualify for SSI?**

A. Generally, to get SSI, the countable resources or assets must not be worth more than $2,000 for an individual. Resources are cash and things the person own and can turn into cash. Examples of resources are bank accounts, property, stocks and bonds.

**Q. What happens if the developmentally disabled person's resources or assets are transferred in order to get under the $2,000 limit?**

A. If the resources of the developmentally disabled person are transferred or given away or sold for less than it is worth, the disabled person may be ineligible for SSI up to 36 months.

**Q. Can the resources or the assets of a developmentally disabled person be placed in a "Special Needs Payback Trust" and still qualify for SSI benefits?**

A. Yes. By putting the assets into a "Special Needs Payback Trust," these monies will not count towards the $2,000 limit on assets which a disabled person is permitted to have and still qualify for SSI. It is very important to have an attorney who has experience in this area to draft this type of Trust or otherwise, an improperly drafted Trust may disqualify the person for SSI benefits until that Trust is exhausted.

**Q. Can the resources or the assets of a developmentally disabled person be placed in an ABLE account and still qualify for SSI benefits?**

A. Yes. By putting the assets into an ABLE account these monies will not count towardsthe $2,000 limit on assets which a disabled person is permitted to have and still qualify for SSI. However, for 2018, a person cannot deposit more than $15,000 per year. So if a person had for example, $25,000 in their own name, then they would need to put the money into a "Special Needs Payback Trust" in order to qualify for SSI as the ABLE account can only accept $15,000 per year. A person can have up to $100,000 in their ABLE account and still qualify for SSI.

**Q. Should a parent or relative contribute their own money into an ABLE account?**

A. No. An ABLE account has a Payback feature which means that upon the passing of the disabled person, before any monies in the account would be paid to the designated beneficiaries on the account, Medicaid would be entitled to be reimbursed for any monies which they paid during the lifetime of the disabled person. If a parent or relative wanted to contribute their own money to benefit the disabled person, then a Special Needs Trust should be set up and there would be no Payback requirement.

## Child Support Payments Will Reduce or Eliminate SSI Benefits

In general, if a child is entitled or receiving SSI payments in the amount of $600 per month and there are child support payments made for that child in the amount of $500 per month, then the SSI benefit will be $100 per month. In order to avoid the child support reducing the SSI benefit, the child support order would need to state that the child support payments are to be irrevocably assigned to the Special Needs Irrevocable Pay Back Trust and that the payments are to be made by the non-custodial parent to the custodial parent as the custodial parent is the Trustee of the Special Needs Irrevocable Pay Back Trust. (There are two different types of Special Needs Trusts and the parents would not leave their inheritance into this Pay Back Trust, but rather leave it into the other Special Needs Trust.)

Attorney Robert H. Farley, Jr. can work with your child support attorney to make sure that the child support order is correctly worded, so the child can get the maximum amount of SSI benefits without a child support reduction.

## SSI Benefits for Disabled Children (Under Age 18)

When a disabled child (under the age of 18 years) is applying for SSI benefits the income and resources of his or her parents are considered.  Social Security has many different rules in determining whether children can financially qualify for SSI benefits.  Social Security will look at the family income and resources and calculate whether there are 1 or 2 persons in the household and calculate the number of children (disabled and non-disabled) in the family.

For example, a single parent with one disabled child who earns around $37,500 per year, should contact Social Security to see if the child qualifies for SSI.  If the same single parent has 3 children (1 disabled and 2 non-disabled) and earns around $46,500 per year, then he or she should contact Social Security to see if the disabled child qualifies for SSI.

If both parents live in the same household and they have one disabled child and their combined income is approximately $46,500 per year, then they should contact Social Security to see if the child qualifies for SSI.  If the same parents have 3 children (1 disabled and 2 non-disabled) and have a combined income around $55,500 per year, then they should contact Social Security to see if the disabled child qualifies for SSI.

Please remember that the above numbers are approximations and there is no downside to contacting Social Security and obtain further information as to whether your disabled child qualifies for SSI.

## Obtaining Medicare Health Coverage for a Disabled Young Adult Currently Receiving SSI Benefits

SSI at Age 18 – Most disabled young adults obtain SSI Benefits (Supplemental Security Income) at the age of 18 if they are disabled and have less than $2,000 in their own name.  The SSI Benefits are for those persons who have not paid into the Social Security system and obtain enough credits to be classified as a disabled worker.  For those persons who have earned enough Social Security credits, than they will receive SSDI Benefits (Social Security Disability Insurance).

Benefits of Obtaining SSDI – When a person obtains SSDI, they will also receive Medicare health coverage 24 months thereafter.  In other words, after a person is collecting SSDI for two years, then they will receive Medicare health coverage.

How a Disabled Young Adult can Qualify for SSDI – A disabled young adult can qualify for SSDI if they became disabled before age 24 and earned six Social Security work credits.  A worker can earn up to a maximum of four Social Security credits per year.  In the year 2020 the disabled person must earn $1,410 to get one Social Security or Medicare work credit and $5,640 to get the maximum four credits for the year.  If, for example, the disabled person earned $3,000 in 2020, then they would have earned two credits for the year.  If the disabled worker has not obtained the six Social Security credits by age 24, then he or she will need to obtain more than those six credits depending upon their post

24 age. (Not every kind of work counts towards Social Security credits as, for example, children younger than age 21 who do household chores for a parent (except a child age 18 or older who works in the parent's business)).

If a parent of a disabled person has paid into Social Security and then the parent either becomes disabled or retires or dies, then their disabled son or daughter will receive SSDI benefits and the disabled person will receive Medicare Health Coverage 24 months thereafter.

## Guardianship When the Disabled Child Turns 18

In Illinois, the law considers a "disabled person" to be a person 18 years or older, who because of mental retardation or mental illness, or physical incapacity or developmental disability, is unable to fully manage his or her own personal or financial affairs in a safe manner and is therefore in need of a guardian.

The court may appoint a "guardian of the person" or a "guardian of the estate" or appoint both, a "guardian of the person and estate." A guardian of the person refers to the authority of the guardian to make decisions concerning the personal and physical care of the "disabled person," including health care decisions and living arrangements. A guardian of the estate refers to the authority of the guardian to handle the money, property, bills and other financial affairs of the "disabled person."

**Frequently Asked Questions:**

**Q. What happens if I don't obtain guardianship over my disabled adult son or daughter?**

A. With respect to medical care, sometimes doctors and hospitals will accept the consent of the parents, but this does not always happen. With respect to living and social arrangements, if a "friend" or "stranger" persuades the disabled person to socialize or live with them, generally law enforcement will honor the desires of the disabled person if there has been no guardian of the person appointed. Without appointment of a guardian, all the parents can do is try to persuade their adult child to choose differently.

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**Q. If my developmentally disabled adult son or daughter gives me "Power Of Attorney," will this avoid the need for guardianship?**

A. No. Many parents have incorrectly been told to get "power of attorney" from their disabled child. In order for a power of attorney to be valid, the person granting or signing the power must have the legal capacity to consent and fully understand what he or she is doing, which generally does not exist for a person who is developmentally disabled. Even assuming that the developmentally disabled person is high functioning and has some capacity to consent, that person would also have the right to cancel or revoke the power at any time in the future.

**Q. If I am appointed guardian, will I be responsible to pay the disabled person's bills out of my funds?**

A. No. You are not responsible to pay any debts from your own assets.

## Procedure for Appointment Of Guardianship

A Petition for Guardianship is filed in Court after the disabled person has turned 18 years of age. The Petition is usually filed by the proposed guardian in the County where the disabled person lives. A doctor's report about why a guardianship is necessary also should be filed at this time. This doctor's report is good for 90 days from the date of the report until the Petition for Guardianship is filed in the Clerk's office. The person filing the petition must send a notice of the time and place of the hearing to the disabled person by way of "Summons" and by way of "Notice" to his or her immediate relatives - parents and adult siblings. The purpose of the hearing is for the judge to decide whether the person is a "disabled person" under the law. If the judge makes a finding of disability, the judge will appoint a guardian of the person, the estate, or both. I recommend that appointment of the Guardian should be for both the person and estate, as the Guardian will need to be appointed of the estate if an ABLE Account is to be opened in the future.

## "Sample Forms" for Appointment of Guardianship

Sample forms can be viewed at www.farley1.com. The "Petition for Guardianship" should be filed in the County where the disabled person resides. Every County has their own forms and own procedures and some of these forms are available online from the Clerk of the Circuit Court in the county where the disabled person resides.

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For a disabled person residing in Cook County, Illinois, there is a Free Help Desk to assist persons filing for Guardianship in Room 1202 of the Daley Center. They are open from 9:00 a.m. to 1:00 p.m. Monday through Friday, when the Courts are open. If both parents are seeking to be appointed Co-Guardians then both must appear at the Free Help Desk together.

## Mental Health Services for Children and Adults

### CHILDREN MENTAL HEALTH SERVICES (UNDER THE AGE OF 21)

In January 2018, a Class Action Settlement (Consent Decree) was entered in Federal Court in Chicago, *Illinois, N.B. v. Norwood*. Attorney Robert H. Farley, Jr. is Class Counsel in this case.

All persons who are under the age of 21 and are Medicaid eligible in the State of Illinois, who have been diagnosed with a mental health or behavioral disorder and who have received a recommendation for intensive home or community base services to address their disorders, are entitled under the Court Settlement to receive these home or community base services (residential and in-home). This Settlement will provide needed community base services to these persons who have either a mental health or behavioral disorder.

Under the terms of the Settlement, the person under the age of 21 must be "Medicaid Eligible." Every person 18+ should be Medicaid eligible if they have less than $2,000 in his or her name. For children under the age of 18, in order to be Medicaid eligible, then the child would need to qualify for Medicaid and the family income will determine whether the child qualifies for Medicaid. **If the child is under the age of 18 and the family cannot obtain a Medicaid card for the child due to the family income, then please contact Attorney Robert H. Farley, Jr. as there is a legal path to secure Medicaid funding for the child's mental health or behavioral disorder.**

Additional information regarding this Class Action Settlement will be posted at www.farley1.com You can contact Attorney Robert H. Farley, Jr., via his email or call him at his office.

### ADULT MENTAL HEALTH SERVICES (21+)

Adults with a mental health condition are entitled to the necessary services to address their disability. Funding for residential and in-home services are available, but it can be a challenge to obtain these services. **If the disabled adult is unable to obtain needed mental health services, then please contact Attorney Robert H. Farley, Jr. as there is a legal path to secure these needed services.**

# Physical Disability Services for Children and Adults

## PHYSICAL DISABILITY SERVICES

The Home Services Program (HSP) provides services to individuals with severe disabilities so they can remain in their homes and be as independent as possible. The disabled person has a physical disability which requires the assistance of a personal attendant for personal care and household tasks. (If the parent or caregiver of the disabled person is able to provide the assistance to the disabled person, then the State of Illinois will not provide funding when the caregiver is present). This program was created to provide an alternative to institutional care to Children and Adults who qualify for Medicaid. There is no Waiting List for this program. For those individuals who have both a developmental disability and a physical disability and who are on the Waiting List for developmental disability services, they could access services in this program and still be on the Waiting List for developmental disability services.

# Nursing Services In-Home Programs – RN/LPN

## TWO NURSING SERVICES PROGRAMS

### 1. Medically Fragile Technology Dependent (MFTD) Program

The MFTD Program provides skilled nursing services and other services to individuals under the age of 21 in their home and these services can continue past their 21st birthday if they were enrolled in this program prior to their 21st birthday. These services are provided based on the fact that because of the severity of their physical illness or disability, they would require the level of care appropriate to a hospital or skilled nursing facility. For children under the age of 18 in the MFTD program, family income is waived in order to qualify for Medicaid. There is no Waiting List for this program.

### 2. Nursing and Personal Care Services (NPCS) Program

For those children under the age of 21 who are in need of skilled nursing services but do not qualify for the MFTD program, skilled nursing services will be provided based on medical necessity. For children under the age of 18 in the NPCS program, family income is not waived in order to qualify for Medicaid. There is no Waiting List for this program.

## Supportive Living Program for Adults

The Supportive Living Program (SLP) is an alternative to nursing home care for low-income persons with physical disabilities (ages 22-64) and for older persons (65+). Each Medicaid-eligible resident must have income equal to or greater than the current SSI and must contribute all but $90 each month to the provider for lodging, meals, and services. The $90 is to be kept by the resident as a personal allowance to use as the resident wishes. When sharing a room, a Medicaid-eligible resident is required to contribute no more than one half of the current SSI rate for a married couple minus the $90 personal allowance.

# Workshop Presentation by Robert H. Farley, Jr.

## "How to Navigate the Illinois Disability System"

For those Parents and Educators who have not been able to attend the Workshop Presentation by Robert H. Farley, Jr., the following Introduction and Concluding remarks from the Workshop, will give you a better understanding of a person's entitlement to disability funding and services under the law.

### INTRODUCTION

I am Robert H. Farley, Jr. and I have been practicing law for approximately 40 years. I have argued cases before the Illinois Supreme Court, the United States Federal District Court, the United States Court of Appeals and 2 clients have prevailed before the United States Supreme Court. I am an attorney who represents children and adults with disabilities 24/7. I am also the proud father of Ryan (age 37), a severely developmentally disabled person who functions at a mental age of approximately 1½ to 2½ years

My story begins over 20 years ago. In 1997, as Ryan, was approaching his 14th birthday, needed to go into a residential facility in order to address his aggressive behaviors which began a few years prior and had escalated. There were no appropriate children residential programs in Illinois to properly address his needs. The School District agreed that Ryan needed a residential facility and finally the State of Illinois agreed that Ryan needed a residential facility out of state. Plane tickets were purchased to bring Ryan to Bancroft in the State of New Jersey. At the last minute, the State of Illinois refused to sign the contract with Bancroft as the State claimed that the cost for his care was too great. Under Special Education Law, a disabled child is entitled to a free appropriate education to address his or her disability, irrespective of the cost. I told the State of Illinois that Ryan required a 1:1 aide during school and he also required a 1:1 aide in the group home. In the event that Ryan's condition stabilizes in the future, I told the State that, it may be possible that he no longer needs a 1:1 aide in his home, which will reduce the cost. Despite my efforts, the State still refused to sign the contract.

When the State told me that they would not sign the contract to provide for Ryan's care at Bancroft, I was livid. I could not sleep and I returned to my office the same day around midnight and I faxed the State a letter which gave them 24 hours to reconsider their position, otherwise I will be in Federal Court seeking an immediate Court Order requiring the State of Illinois to fund Ryan's out-of-state residential placement. I also informed the State that I would file a Class Action lawsuit on behalf of the other children in the State of Illinois who were being horsed around by their failure to pay for an appropriate residential education.

The State called me before the expiration of the 24 hours and their conversation started off that "they have heard wonderful things about Ryan" and that they will now sign the contract with Bancroft to provide the necessary funding which Ryan requires. This conversation in 1997 predated the Internet and Skype, thank God, because during the entire conversation with the State of Illinois, I was making certain hand gestures.

As a parent and as an attorney, I wanted to know what would happen to Ryan after he exited Special Education. I wanted to know why the State of Illinois always ranked as one of the worst states in providing disability services. I wanted to know why other States were providing better services and would I have to move to another state in order for Ryan to get good adult services after Special Education. After Ryan's condition stabilized, I talked to lawyers throughout the United States and as far as Hawaii. I talked to persons and agencies throughout the country about disability services and I talked to the people who assemble the data and publish the rankings of all 50 States in providing disability services. I came to the conclusion, which was supported by the key person who publishes the ranking of all the States, that the reason a State provides good and extensive disability services is either because the Governors of those States had a family member with a disability and they made it a priority to serve people with disabilities or the State had been successively sued in Court and is now required to provide good disability services. In the case of Illinois, our Governors have not had a family member with a disability and most of our Governors end up in the federal penitentiary, because they are more concerned with helping their crooked buddies then God-forbid, your disabled son or daughter. Additionally, Illinois had not been sued in Court to provide disability services to your children aging out of Special Education.

In 2000, I filed a Federal Lawsuit which grew to 11 families who were seeking funding from the State of Illinois for either Home Base Support Services or a Group Home. The Federal District Court ruled against us and I appealed the case to the United States Court of Appeals. The United States Department of Justice joined with me in the appeal and the Court of Appeals ruled that persons with disabilities are entitled to sue the State of Illinois for community based services under the Americans with Disabilities Act (ADA). After the appeal, the case was settled and all 11 persons with disabilities received effectively life-time community based funding.

Since 2000, Class Action lawsuits have been filed on behalf of persons with disabilities and there are now Court orders (Consent Decrees) which protect the rights of these persons even today. During the past 10 years, I have successfully filed 7 Federal Class Action lawsuits against the State of Illinois to secure funding for services and protect the legal rights for persons with disabilities, and more Class Actions will be forthcoming. In one of these cases, the United States Department of Justice, for the second time, joined with me in the lawsuit against the State of Illinois. In one Court filing, the Department of Justice stated, "Robert Farley is an experienced advocate . . ."

Simply put, people with disabilities are entitled to funding for services to address their disabling condition. Parents need to have the mindset that their child has an entitlement to disability services, irrespective of the cost of providing those services. I have clients who are medically fragile and they receive approximately $250,000 per year for in-home community based nursing (RN/LPN) services for up to 16 hours per day. Another client receives funding for a group home in the approximate amount of $170,000 per year as she requires two aides at all times.

* * * **Workshop Presentation covers the materials in this Book** * * *

## CONCLUDING REMARKS

As Ryan was approaching his 21st birthday and was in his last year of Special Education in his residential program in New Jersey, I wanted Ryan to remain in New Jersey as Bancroft provided an excellent Adult residential program for those exiting Special Education. Although it would have been nice to have Ryan closer to me in Illinois, I believed that it was in the best interest for Ryan to continue in New Jersey as he had made tremendous progress during the past 7 years. (It takes me 1 ½ hours to travel from my office in Naperville to Federal Court in Chicago during rush hour and it only takes me 1 ½ hours to fly to visit Ryan, so it is just another commute for me to go out East.)

I told New Jersey that I wanted to make Ryan a resident of New Jersey and receive Medicaid New Jersey funding for Ryan in the Adult residential program. The case worker from New Jersey told me that I could not apply for funding until Ryan's funding from Illinois ran out. I told New Jersey that they do not have to fund him until the Illinois funding is exhausted, but New Jersey needs to process his application for residential funding. Later I sent a letter/legal memo to the Acting Director of the New Jersey Department of Human Services – Division of Developmental Disabilities, informing her that Ryan is entitled to community based residential funding in New Jersey. (I was aware that New Jersey had previously told an out-of-state family that New Jersey would not provide funding at Bancroft and instead offered to toss the person into a New Jersey State institution.) I told New Jersey that Ryan is entitled to community based services under the ADA and it would be a violation of Federal law to place him in an institution. I told New Jersey that I was one of a handful of attorneys in the United States who has successfully sued a State to obtain community based services and, in that case, the United States Department of Justice joined me in the lawsuit against Illinois. I told New Jersey that if they did not provide the funding for Ryan, then I would reach out to the Justice Department and find out if they wanted to join my lawsuit on Ryan's behalf against New Jersey. I told New Jersey that I consider it my second home as I have a place in New Jersey where Ryan and I can spend a weekend or vacation time together. I told New Jersey that after I litigated Ryan's case against them, then I would file a Federal Class Action lawsuit against New Jersey on behalf of the thousands of persons with disabilities who are on a Waiting List for services.

I was informed by New Jersey approximately 3 to 5 months before his Illinois funding ran out, that New Jersey would fund under Medicaid, Ryan's adult residential treatment at Bancroft. As Ryan's father, this was a very emotional moment for me, as now the Bus can run over me, as Ryan's funding and future is now secure. Now, at some point in time, the Bus is going to run over me and it is also going to run over you, so don't wait forever to take me up on my offer to provide whatever assistance I can, to secure the future for your child.

Thank you.

# Robert H. Farley, Jr., Attorney at Law

Attorney Robert H. Farley, Jr., a graduate of the Northwestern University School of Law, has been providing legal representation to children and adult individuals with disabilities and their families for over twenty-five years in support of their rights, entitlements to adult and children services, guardianship, development of customized estate plans, special needs trusts, and public benefits.

Mr. Farley's law practice is exclusively focused on representing children, young adults, and adults obtaining government services and benefits due to their disability, whether they are developmentally disabled, mentally ill, physically disabled, elderly or medically fragile.

Mr. Farley has argued numerous cases before the Illinois Supreme Court and before the Federal District and United States Court of Appeals. He was the lead attorney in the precedent-setting case in the State of Illinois where the United States Court of Appeals held that Mr. Farley's developmentally disabled clients were entitled to sue the State of Illinois under the Americans with Disabilities Act (ADA) to receive services in the least restrictive setting or community. In two of Mr. Farley's federal cases, the United States Department of Justice has filed legal briefs in support of the claims raised by the disabled. The United States Department of Justice stated in one Court filing, that "Robert Farley is an experienced advocate. . ."

Mr. Farley has secured community-based funding for children and adults with disabilities even though they had been previously denied funding by the State of Illinois because the State did not consider them to be an emergency or a priority for funding.

Mr. Farley has successfully filed 7 Federal Class Action Lawsuits against the State of Illinois during the past 10 years to secure funding for services and protect the legal rights for persons with disabilities. No other attorney in the United States has achieved this level of success for persons with disabilities.

Mr. Farley has received from "The Arc of Illinois" the "President's Award -
For Outstanding Legal Advocacy On Behalf Of People with Developmental Disabilities in Illinois." From "Advocates United," Mr. Farley received an award for "Extraordinary Dedication & Tireless Work for Quality Life Choices for All People with Disabilities."

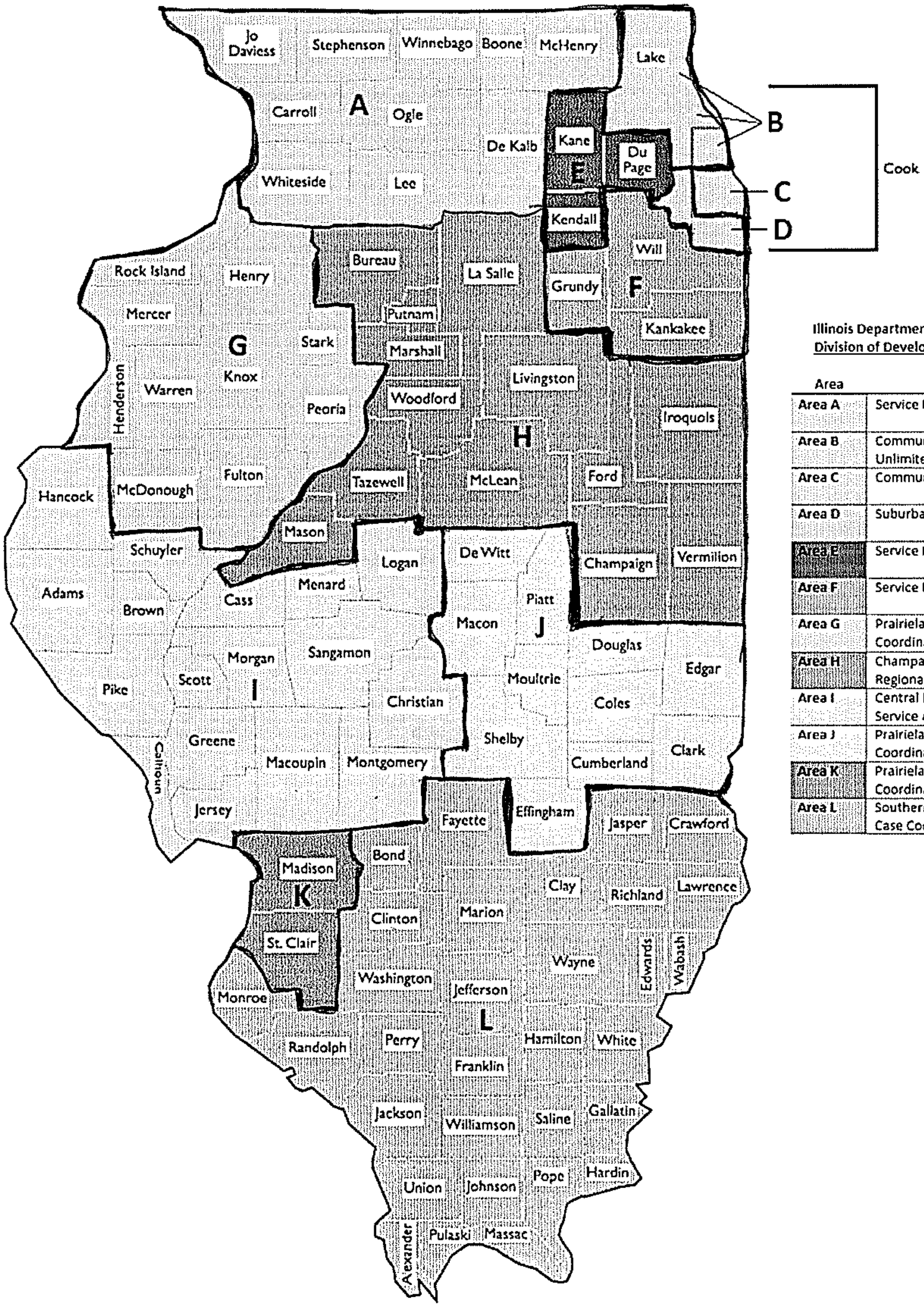
Mr. Farley speaks and writes frequently on the topics of disability, disability rights and responsibilities under the law, and advocacy for children and adults with disabilities.

Mr. Farley is the proud father of four children, including Ryan, his 37 year old developmentally disabled son.

**Exhibit A**

• Illinois Department of Human Services • Division of Developmental Disabilities •

## Independent Service Coordination Agency Map



Illinois Department of Human Services
Division of Developmental Disabilities

| Area | ISC Agency |
|---|---|
| Area A | Service Inc. of Illinois |
| Area B | Community Alternatives Unlimited |
| Area C | Community Service Options |
| Area D | Suburban Access Inc. |
| Area E | Service Inc. of Illinois |
| Area F | Service Inc. of Illinois |
| Area G | Prairieland Service Coordination Inc. |
| Area H | Champaign County Regional Planning Commission |
| Area I | Central Illinois Service Access |
| Area J | Prairieland Service Coordination Inc. |
| Area K | Prairieland Service Coordination Inc. |
| Area L | Southern Illinois Case Coordination Services |

Exhibit A

# Independent Service Coordination Agencies

**Area A** (Boone, Carroll, De Kalb, Jo Daviess, Lee, McHenry, Ogle, Stephenson, Whiteside and Winnebago)

Service Inc. of Illinois
3482 Pyramid Drive
Rockford, IL 61109
(815) 339-0740
www.svcincofil.org

**Area B** (Lake, Cook)

Community Alternative Unlimited (CAU)
8765 W. Higgins Rd., 3rd Floor
Chicago, IL 60631
(773) 867-4000
www.cau.org

**Area C** (Cook)

Community Service Options (CSO)
6845 S. Western Ave.
Chicago, IL 60636
(773) 471-4700
www.cso1.org

**Area** D (Cook)

Suburban Access Inc.
900 Maple Ave.
Homewood, IL 60430
(708) 799-9190
www.suburban-access.org

**Area E** (DuPage, Kane and Kendall)

Service Inc. of Illinois
1919 South Highland Ave., Suite A #230
Lombard, IL 60148
(630) 425-2350
www.svcincofil.org

**Area F** (Grundy, Kankakee and Will)

Service Inc. of Illinois
1740 West Mc Donough Street
Joliet, IL 60546
(815) 741-0800
www.svcincofil.org

**Area G** (Fulton, Henderson, Henry, Knox, McDonough, Mercer, Rock Island, Stark, Warren and Mercer)

Prairieland Service Coordination Inc.
244 East Main Street
Galesburg, IL 61401
(309) 921-9102
www.psci.info

**Area H** (Bureau, Champaign, Ford, Iroquois, LaSalle, Livingston, Marshall, Mason, McLean, Putnam, Tazewell, Vermillion and Woodford)

Champaign County Regional Planning Commission (CCRPC)
1776 E. Washington St.
Urbana, IL 61802
(217) 328-3313
www.ccrpc.org

**Area I** (Adams, Brown, Calhoun, Cass, Christian, Greene, Hancock, Jersey, Logan, Macoupin, Menard, Montgomery, Morgan, Pike, Sangamon, Schuyler and Scott)

Central Illinois Service Access (CISA)
101 Madigan Dr.
Lincoln, IL 62656
(217) 732-4731
www.cisagroup.org

**Area J** (Clark, Coles, Cumberland, DeWitt, Douglass, Edgar, Effingham, Macon, Moultrie, Piatt and Shelby)

Prairieland Service Coordination Inc.
1670 South Taylorville Road
Decatur, IL 62521
(217) 362-6128
www.psci.info

**Area K** (Madison and St. Clair)

Prairieland Service Coordination Inc.
2130 A Vadalabene Drive
Maryville, IL
(618) 288-1897
www.psci.info

**Area L** (Alexander, Bond, Clay, Clinton, Crawford, Edwards, Fayette, Franklin, Gallatin, Hamilton, Hardin, Jackson, Jasper, Jefferson, Johnson, Lawrence, Marion, Massac, Monroe, Perry, Pope, Pulaski, Randolph, Richland, Saline, Union, Wabash, Washington, Wayne, White, Williamson)

Southern Illinois Case Coordination Services (SICCS)
325 South Poplar, PO Box 588
Centralia, IL 62801
www.illinoislifespan.org

Exhibit B

# “Seeking Services” Category

## Person needs services within one year

The State of Illinois will consider a disabled person is “Seeking Services” if he or she satisfies 1 of the following 21 categories.

1. Individual or care giver will need support within the next year in order for the individual to continue living in their current situation.
2. Person has a care giver (age 60+) and will need support within the next year.
3. Person has an ill care giver who will be unable to continue providing care within the next year.
4. Person has behavior(s) that warrant additional supports to live in their own home or family home.
5. Individual personal care needs cannot be met by current care givers or the person’s health has deteriorated.
6. There has been a death or other family crisis, requiring additional supports.
7. Person has a care giver who would be unable to work if services are not provided.
8. Person or care giver need an alternative living arrangement.
9. Person has graduated or left school in the past 10 years.
10. Person is living in an inappropriate place, awaiting a proper place (can manager for the short term; e.g., persons aging out of children’s residential services).
11. Person moved from another state where they were receiving residential, day and/or in-home supports.
12. The state has plans to assist the person in moving within the next year (from a state operated Intermediate Care Facility for People with Developmental Disabilities, nursing home or state hospital).
13. Person is losing eligibility for Department of Children and Family Services supports in the next year.
14. Person is losing eligibility for Early Periodic Screening, Diagnosis and Treatment supports in the next year.
15. Person is losing eligibility for Intermediate Care Facility for People with Developmental Disabilities supports in the next year.
16. Person is losing eligibility for Medically Fragile/Technology Dependent Children’s Waiver supports in the next year.
17. Person is residing in an out-of-home residential setting and is losing funding from the public-school system.
18. Person is losing eligibility for Individual Care Grants support through the mental health system in the next year.
19. Person is leaving jail, prison or other criminal justice setting in the next year.
20. Person wants to leave current setting within the next year.
21. Person needs services within the next year for some other reason.

    (Specify: ________________________________________)

Exhibit C

Federal Consent Decree (Court Order) Defining "Crisis Criteria" for Adults

Case: 1:05-cv-04331 Document #: 549 Filed: 06/15/11 Page 1 of 41 PageID #:11108

IN THE UNITED STATES DISTRICT COURT
FOR THE NORTHERN DISTRICT OF ILLINOIS
EASTERN DIVISION

| | | |
|---|---|---|
| STANLEY LIGAS, et al., | ) | |
| | ) | |
| Plaintiffs, | ) | No. 05 C 4331 |
| | ) | |
| Vs. | ) | Chief Judge Holderman |
| | ) | Magistrate Judge Cole |
| JULIE HAMOS, et al., | ) | |
| | ) | |
| Defendants. | ) | |
| | ) | |

CONSENT DECREE

* * *

21. Class Members Who Reside in a Family Home and Are Determined to be in a Situation of Crisis.

(a) For purposes of the Decree, an Individual is in a situation of "Crisis" if he or she is at imminent risk of abuse, neglect, or homelessness. The provision of interim emergency services (including interim placement in an ICF-DD where no placement in a Community-Based Setting was immediately available) will not necessarily exclude the Individual from being deemed to be in a situation of Crisis. Some examples of circumstances that constitute Crisis include, but are not limited to circumstances:

(i) where the Individual's caregiver(s) are deceased;
(ii) where the Individual's caregiver is unable to address the support needs of the Individual, thereby jeopardizing the Individual's health, well-being, and/or safety;
(iii) where physical and/or mental injury and/or sexual abuse is being inflicted on the Individual;

(iv) where the Individual is homeless or without domicile; or

(v) where the Individual's behaviors (e.g., verbal and/or physical aggression, bodily harm to self and/or others) put the Individual and/or family member(s) at risk of serious harm.

(b) If, following a screening, the Individual who is determined to be in Crisis requests appropriate Community-Based Services to be provided in the Family Home or requests placement in a Community-Based Setting, Defendants will promptly develop, in conjunction with the Class Member, a Transition Service Plan. Transition Service Plans for such Class Members shall be developed as set forth in Section VII, above.

(c) Defendants shall ensure that all Class Members who are determined to be in a situation of Crisis, and who request to receive Community-Based Services and/or placement in a Community-Based Setting, receive such services and/or placement in such setting expeditiously. If a Class Member is determined to be in Crisis and then moves into an ICF-DD before Defendants are able to provide a placement in a Community-Based Setting, that change in the Class Member's residential status will not in itself change the determination of Crisis or change the Defendants' obligation to place the Class Member in a Community-Based Setting expeditiously, provided that, at the time of transition to a Community-Based Setting, the Class Member requests placement in a Community-Based Setting, as confirmed and documented at that time. There is no limit to, or cap upon, the number of Class Members in Crisis who shall be served pursuant to the Decree.

Exhibit D

# Adult Crisis Criteria for Funding – Effective April 16, 2008

The crisis criteria for imminent risk of abuse, neglect, or homelessness are the highest funding priorities of the Division of Developmental Disabilities (DDD) for adults who are 18 years or older. Each individual's urgency of need must be reflected in the PUNS database. In submitting the request for crisis authorization, the Pre-Admission Screening/Independent Service Coordination (PAS/ISC) agency must share in writing with the network staff the proposed plan(s) that have been arranged and/or scheduled for service implementation. It is expected that services will be implemented generally within a 24 to 72 hour period. The local PAS/ISC agency shall report all instances of abuse, neglect, and/or homelessness to the appropriate entity(s) as directed by applicable state, federal, and/or local laws, rules, regulations, and policies.

The crisis criteria apply to Waiver-Funded Adult Home-Based Support Services (AHBS) and Community Integrated Living Arrangements (CILAs). These criteria do not apply to Respite, Community Living Facilities (CLFs), privately operated Intermediate Care Facilities for Individuals with Developmental Disabilities (ICFs/DD), and Supported Living Arrangements (SLAs).

The Division's decision regarding the type of service to authorize will be based on the specific needs of the individual. In reviewing whether or not the individual meets the crisis criteria, the DDD will consider, but not limit itself to, the following, which are presented in priority order:

1. The death of the caregiver(s);
2. The caregiver is unable to address the support needs of the individual, thereby jeopardizing the individual's health, well-being, and/or safety needs;
3. The physical and/or mental injury and/or sexual abuse inflicted on the individual;
4. The status as a homeless/undomiciled individual;
5. The individual's behaviors [e.g., verbal and/or physical aggression, bodily harm to self and/or others] that put the individual and/or family member(s) at risk of serious harm.

## CASE 1 - EXAMPLE OF NEGLECT:

The individual remains at home without any support services. Her physician referred her to a nutritionist who recommends a high protein diet. She is 4' 8" and weighs 62 pounds, which is down from 82 pounds within a two-year period. It is unknown whether the mother has placed the individual on the recommended diet.

The individual's communication is basically echolalic. The local PAS/ISC agency reports that she pulls her hair, scratches her face, bangs her head against objects, hits self and others, and screams. She has also been observed remaining in a fetal position for extended periods of time. While the mother is at work during the day, the younger brother (19 years old) serves as her caregiver. The mother

**Exhibit D**

reported to the local PAS/ISC agency that there have been instances in which she has returned home early from work to find her daughter alone in the home, meals not prepared for her, all lights turned off, and the whereabouts of the son unknown. The mother does not have any other family members and/or friends to help support her daughter's needs while she is at work. The mother wants her daughter to remain at home. The individual is 21-years-old with Severe Mental Retardation, Pervasive Developmental Disorder, Borderline Diabetes, and Sensitive Bowel Condition.

## CASE 2 - EXAMPLE OF HOMELESSNESS AND NEGLECT:

The individual is currently homeless. While the mother was hospitalized, an eviction notice was served for nonpayment of rent. Since the mother's recent discharge from the hospital, she has not been in contact with her children and they are uncertain about her whereabouts. A brother and sister who had been staying at the house moved into a one-bedroom apartment. They are unable to care for their sister with a developmental disability because of their work schedules and limited space in the apartment. On average, the sister and brother work 10-12 hours per day.

The individual has been staying at the house alone without support and supervision. The house is not clean (e.g., several bags of garbage in the kitchen, dirty clothes piled on bed and in hallway, and dirty dishes and cooking utensils are on the counter top and stove and in the sink). She invites strangers in the home. After such visits the individual ends up missing money, food, and belongings. An elderly aunt and uncle, who are concerned, check on her periodically. They report that the individual is not consistently taking her medications. The individual is her own guardian. The proposed service provider is attempting to arrange temporary in-home support services; however, the individual has been uncooperative because she believes that "Mom will be home soon." The individual does not have a telephone. In her current setting she lacks the necessary skills to make sound choices that assure her safety and well-being.

The individual is 30 years old with Moderate Mental Retardation and Bipolar Disorder

The individual is 30 years old with Moderate Mental Retardation and Bipolar Disorder.

## CASE 3 - EXAMPLE OF ABUSE OF AN ELDERLY CAREGIVER:

The individual lives with his mother who is 75 years old. He has been terminated from two supported employment opportunities due to threatening other co-workers if they did not complete his work task(s) for him. The mother is a single caregiver. The father died three years ago. There are no other adults in the home and/or other family members in/near the area to help address the support needs of the individual.

The neighbors have observed the individual screaming at, pushing, and hitting his mother when she does not respond to his demands in a timely manner. He is 5' 9" and weighs 215 pounds. His mother is 5' 1" and weighs 120 pounds. She is physically unable to manage his aggressive behaviors toward her, thereby jeopardizing her own safety and well-being. On numerous occasions the police have been called in response to the individual's aggressive behaviors toward his mother.
The individual is 40 years old with Moderate Mental Retardation and Depression.

Exhibit E

# Children Crisis Criteria for Funding – Effective April 16, 2008

The crisis criteria for imminent risk or abuse, neglect, or homelessness are the highest funding priorities of the Division of Developmental Disabilities (DDD) for children who are 3 to 17 years old. Each child's urgency of need must be reflected in the PUNS database. In submitting the request for crisis authorization, the Pre-Admission Screening/Independent Service Coordination (PAS/ISC) agency must share in writing with the network staff the proposed plan(s) that have been arranged and/or scheduled for service implementation. It is expected that services will be implemented generally within a 24 to 72 hour period. The local PAS/ISC agency shall report all instances of possible abuse, neglect, and/or homelessness to the appropriate entity(s) as directed by applicable state, federal, and/or local laws, rules, regulations, and policies.

The crisis criteria relate to Waiver-Funded Children's Home-Based Services (CHBS) and children's Group Homes (CGHs – Program 17D). The emergency crisis criteria also apply to admissions to Child Care Institutions (CCIs – Program 19D). These criteria do not apply to respite and Skilled Nursing Facilities/Pediatric (SNFs/Ped). Children who are wards of the State are not eligible for funding authorized by the DDD.

The Division's decision regarding the type of service to authorize will be based on the specific needs of the child. In reviewing whether or not the child meets the crisis criteria, the DDD will consider, but not limit itself to, the following, which are presented in priority order;

1. The caregiver is unable to keep the child safe;
2. The caregiver is unable to meet the child's support needs. The family dynamics (e.g., multiple children with disabilities dependent upon the caregiver) as correlated with the medical, physical, and/or behavioral needs of the child place demands on the family that put the child and/or family member(s) at serious risk; or
3. The child's behaviors (e.g., verbal and/or physical aggression, bodily harm to self and/or others) put the child and/or family member(s) at risk or serious harm.

### CASE 1 – EXAMPLE OF IMMINENT RISK OR NEGLECT:

The 8 year old child attends school for half days. The father works part time while the child is at school. The mother works full time. The family receives 2 hours per week or respite services for the child. The child resides with his parents and three younger siblings (ages range from 2 to 6 years old). The siblings are active and healthy and do not have a disability. The father is the sole caregiver for the four children.

The child requires constant monitoring and provision of physical care. Because of the child's physical needs, the caregivers must be trained and responsible for monitoring his condition. The family reports increased stress of caring for the son as they have reported to the PAS/ISC agency that they want him to remain in the family home, but are feeling overwhelmed with his care. The father recently questioned whether he can continue to keep the child home as he feels he is not able to keep up with all of the child's needs. The child does not sleep well and the father is up most of the night trying to comfort him and get him back to sleep. The father reports that, at times, he is unable to care for his son and leaves the child in bed for periods of time without attending to his needs. The father feels very guilty about this, but he reports not knowing what else to do.

The child has been diagnosed with Severe Mental Retardation, Seizure Disorder, and Severe Neurological Deficits, including motor impairments. The child has cortical vision loss. He is non-verbal and non-ambulatory. The child takes multiple seizure medications but continues to have breakthrough seizures daily and some of the seizures are severe.

### CASE 2 – EXAMPLE OF IMMINENT RISK OF HOMELESS:

Two brothers are currently receiving Children Home-Based Services (CHBS). The father who was the primary caregiver for the children recently died. The mother works full time. The two children are larger in height and weight than their mother, thereby making it difficult for her to physically address their support needs. The physical stature of the boys, their overwhelming support needs, and the mother's work schedule contribute to the mother's inability to care for her children. Until residential services for the children can be identified and authorized, the local PAS/ISC agency has obtained respite services for both children. There are no other family members in/near the area to help the mother address the support needs of the children.

Both children have been diagnosed with Severe Mental Retardation and Autism. One child has a diagnosis of epilepsy and controlled seizures. The other child, if not closely monitored, attempts to run away from the home during the night. Both children exhibit pica behavior, severe tantrums, and incontinence. They use pull-up undergarments and smear feces.

### CASE 3 – EXAMPLE OF IMMINENT RISK OF ABUSE DIRECTED TOWARD A YOUNGER SIBLING AND MOTHER:

The child is living with his mother, stepfather, and two younger sisters, ages 4 and 7. The child has been observed kicking, hitting, pushing, and biting self and others. He recently attempted to push his 4 year old sister down a flight of stairs during an episode of agitation. His 7 year old sister is frightened of him and starts to cry when he enters the room. His parents are unable to deter their son's aggressive behavior, which has been focused on his sisters and most recently on his mother.

As a result of the ongoing severity and frequency of his aggressive behaviors toward family members coupled with his size and strength, the family is unable to manage the child in the home. The child exhibits aggressive behaviors 10 to 15 times per day. The mother is seven months pregnant. The obstetrician has advised the mother that addressing her child's severe behaviors and extensive support needs is detrimental to her health and welfare of the younger siblings and her unborn baby.

**Exhibit E**

The biological father has refused to assist with the care of the child. The family has received respite services but the respite provider has had difficulty managing his behaviors and has indicated to the family that they feel he needs more intensive services. After further discussions with the family and local PAS/ISC, it is felt that the child's aggressive outbursts toward his younger sisters and mother are putting them at risk of physical harm.

The child is 11 years old with Severe Mental Retardation, Autism, Intermittent Explosive Disorder, and Seizure Disorder.

# Notes:

# Notes:

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