

“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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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.

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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 child is not entitled to disability funding or services and that he or she does not meet the “Crisis” criteria to obtain funding.

If any person tells you that your child 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 consultation.

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

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 Pre-Admission Screening Agency/Independent Service Coordination Agency to get on “Waiting List.”

- DuPage County – *PACT, Inc.* 630-960-9700
- Will, Kankakee, Grundy County – *Service, Inc.* 815-741-0800
- Kane, Kendall County – *Day One Network*..... 630-879-2277
- 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..... 773-884-1000

(For a List of All Agencies – See Exhibit “A”)

2. **State of Illinois will not pull your child’s name off the “Waiting List” if your child is classified as “Future Planning.”** You want your child to be classified as “Emergency” or “Critical.” As the result of a settlement of Class Action Lawsuit the State of Illinois is required to provide funding/ services for 500 developmentally disabled persons 18 years or older per year. Only those persons classified as an “Emergency” or “Critical” will be pulled as the result of the court settlement.

There are 3 different categories on the “PUNS” List.

- Emergency Need – immediate support needed.
- Critical Need – supports needed within one year.
- Future Planning – support need is 1 to 5 years away.

(See the pages from the “PUNS Manual” for examples of “Emergency” and “Critical” Needs – 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. 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.)

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 D which lists the Children Crisis Criteria.)

4. Now that the parent recognizes that the 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 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 \$1,400 per month. When the disabled person exits special education, the amount is approximately \$2,100 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; and residential.

Adult Services Funding - including but not limited to, personal support; day programming services; residential; respite; behavior intervention; therapies; transportation; and modifications for home, vehicle and adaptive equipment.

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.

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 2013, the maximum SSI payment for an eligible individual is \$710 per month.

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

- A. 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 pay only part of their food and shelter costs, then the SSI monthly benefit may be reduced up to 1/3rd the maximum amount.

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 case. 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.

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 \$35,000 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 \$42,000 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 \$42,000 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 \$50,000 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 contact Social Security and obtain further information as to whether your disabled child qualifies for SSI.

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.

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. The Petition is usually filed by the proposed guardian in the county where the disabled person lives. A doctor's statement about why a guardianship is necessary also should be filed at this time. 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. The judge will decide whether the guardian will have plenary (full) power, or will be authorized to handle only a limited range of matters.

"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.

State of Illinois Definition of a Developmental Disability

There are 2 different ways for 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 all 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.

Services for Children & Adults with Mental Health Issues

If your disabled son or daughter has mental health issues which have resulted in him or her being psychiatrically hospitalized, then you should contact Attorney Robert H. Farley, Jr. to discuss the legal rights of your child to obtain home-based support services or residential services funding from the State of Illinois. There is no charge for this consultation.

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 deals with both simple and routine matters as well as complex legal issues. He 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.

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 priority for funding.

Mr. Farley has four pending federal class action lawsuits against the State of Illinois to provide the necessary funding to children with emotional and behavioral disorders and to medically fragile children and young adults. Due to the fact that irreparable harm and injury will occur to these individuals during the pendency of these lawsuits, Mr. Farley has secured Court Orders to provide the necessary services pending the outcome of the lawsuits.

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. Robert H. Farley, Jr., Attorney, has provided legal representation to individuals with disabilities in a variety of areas, including children and adult services, guardianship, and special needs trust /estate planning.

Mr. Farley is the proud father of four children, including Ryan, his 29 year old developmentally disabled son.

Pre-Admission Screening and Independent Service Coordination Agencies

Network	Agency	Address	Phone
Central	Central Illinois Service Access	301 N. Sixth St. Suite 170 Springfield, IL 62701	(217) 328-3390
		1491 Valle Vista PO Box 817 Pekin, IL 61555	(309) 527-3390
Central	Prairieland Service Coordination	132 S. Water St, PO Box 315 Decatur, IL 62525	(217) 424-0766
Central	Great Rivers Service Coordination	901 W. Morton Ave. PO Box 369 Jacksonville, IL 62651	(217) 243-1330
Central	West Central Service	957 W. Washington St. Pittsfield, IL 62363	(217) 285-5227
North Central	Western Illinois Service Coordination	509 N. Lafayette St. Suite 203 Macomb, IL 61455	(309) 833-1621
North Central	CSO of Rock Island and Mercer Counties	1834 18th Ave. East Moline, IL 61244	(309) 278-0020
North Central	Livingston County Mental Health Board	310 E. Torrance Ave. P.O. Box 504 Pontiac, IL 61764	(815) 844-7708
North Central	Champaign County Regional Planning Commission	1776 E. Washington P.O. Box 17760 Urbana, IL 61801	(217) 328-3313
Northwest	Access Services Northern Illinois	7339 Forest Hills Rd. Loves Park, IL 61111	(815) 282-8824
Southern	Southern Illinois Case Coordination Services, Inc.	519 S. Locust St. PO Box 588 Centralia, IL 62801	(618) 532-4300
Southern	DO Services of Metro East	2900 Frank Scott Pk- wyWest Suite 928 Belleville, IL 62223	(618) 236-7957

Network	Agency	Address	Phone
North Suburban	Options and Advocacy for McHenry County, Inc.	365 Millennium Dr. Suite A Crystal Lake, IL 60012	(815) 477-472
North Suburban	Community Alternatives Unlimited	8765 West Higgins, 3rd Floor Chicago, IL 60631	(773) 867-4000
North Suburban	Pact, Inc.	555 E. Butterfield #201 Lombard, IL 60148	(630) 960-9700
North Suburban	Day One Network	179 Oswalt Ave. Batavia, IL 60510	(630) 879-2277
South Suburban	Suburban Access	925 W. 175 St. FL3 Homewood, IL 60430	(708) 799-6123
South Suburban	Service, Inc.	1730 W. McDonough St. Joliet, IL 60436	(815) 741-0800
Chicago North	Community Alternatives Unlimited	8765 W. Higgins FL3 Chicago, IL 60631	(773) 867-4000
Chicago South	Community Service Options	7575 S. Kostner Chicago, IL 60652	(773) 884-1000
West Suburban	Suburban Access, Inc.	4415 W. Harrison St. Suite 410 Hillside, IL 60162	(708) 449-7257

“Emergency Need” and “Critical Need” Categories

“EMERGENCY NEED” CATEGORY

Persons in this category need to be served now, and cannot wait until a later, perhaps, unspecified date. The criteria for the “Emergency Need” category include:

In-home Emergency Need: Person needs in-home or day supports immediately

- EI1. **Individual needs immediate support to stay in their own home/family home (Short-term - 90 days or less).** This category should be used for short term situations where, perhaps, the care giver is hospitalized or the individual has a short-term illness.
- EI2. **Individual needs immediate support to stay in their own home/family home or maintain their employment status (Long-term).** This category is appropriate for individuals, who can no longer live alone in their own homes due to health or behavioral issues, or where the individual's health or behavior has deteriorated significantly and additional supports are needed to assist the family in keeping the individual at home. This may also apply when the individual requires enhanced supports to maintain employment.
- EI3. **Care giver needs immediate support to keep their family member at home (Short-term - 90 days or less).** This category is appropriate for situations where, for example, the care giver is recuperating from an illness and needs temporary, enhanced supports to assist in care giving.
- EI4. **Care giver needs immediate support to keep their family member at home (Long-term).** This category is appropriate, for example, when the care giver is permanently disabled or terminally ill and needs long-term enhanced supports to keep their family member at home.

Out-of Home Emergency Need (Person needs out-of-home supports immediately)

- EO1. **Care giver is unable or unwilling to continue providing care.** This category is appropriate for individuals who have been left by their care givers at some location (e.g., state-operated developmental center) under the assumption that the person with developmental disabilities will be found quickly and provided with services. The care givers may be nowhere to be found (e.g., left town or state).
- EO2. **Death of the care giver with no other supports (e.g., other family) available.** This category is appropriate for persons living with a single care giver who has died and the person now finds her/himself alone and in immediate need of someone to provide support. The person with developmental disabilities cannot take care of her/himself and will be dangerous to her/himself or others without support being provided.

- EO3. **Person has been committed by the court or is at risk of incarceration.** This is appropriate for persons with developmental disabilities who have been remanded to the state to provide services. A judge/court order is required in this case.
- EO4. **Person is living in a setting where there is suspicion of abuse or neglect.** This is appropriate where there is question of possible abuse or neglect by the care giver or residential staff.
- EO5. **Person is in an exceedingly expensive or inappropriate placement, and immediately needs a new place to live.** This is appropriate for persons who are in a temporary placement (generally residential) that is extremely inappropriate for the person and/or exceedingly expensive such as an acute care hospital, homeless shelter, etc.
- EO6. **Other crisis.** This is appropriate in situations where some other crisis has manifested itself and no support is available to assist the person with developmental disabilities in coping with the crisis. Depending on the situation, stress level, and coping resources, even a minor crisis can be a major concern if support is not available.

PUNS Form Completion Manual (N-01-01-06)

“CRITICAL NEED” CATEGORY

Persons in this category need to be served in the near future (within one year}, but do not requires services immediately (as in the “Emergency Need” category). The criteria for the “Critical Need” categories include:

- C1. **Individual or care giver will need support within the next year in order for the individual to continue living in their current situation.** This category is appropriate for persons whose care giver is clearly progressing toward being unable to provide care for any number of physical/psychological reasons or where the individual him/herself has a deteriorating situation which may require additional supports.
- C2. **Person has an aging care giver (age 60+) and will need supports within the next year.** This applies to situations where the individual and/or family are coping, but due to the age of the care giver or health or situation of the individual, increased supports will be needed in the next year.
- C3. **Person has an ill care giver who will be unable to continue providing care within the next year.** (Ill defined as the primary care giver having a medically diagnosed condition that prevents her/him from fulfilling the care giving role effectively.) This is similar to numbers

one and two in this category except that the condition affecting the care giver is health related rather than necessarily associated with age per se (e.g., age related infirmities or inability to manage physical/psychological stress associated with care giving as opposed to an illness/ infirmity that prevents providing care effectively).

- C4. **Person has behavior(s) that warrant additional support to live in their own home or family home.** This category is appropriate for persons whose behavior is perceived as no longer manageable or controllable. It is important to note that the key consideration is the perception of the care giver(s) if the individual lives with a care giver. Unmanageable behavior in one family might be viewed as eminently manageable in another family because of the coping resources available to the family.
- C5. **Person's personal care needs cannot be met by the current care giver(s), or person's health has deteriorated.** This category is appropriate for persons whose health/physical situation has progressed to a stage wherein the care giver(s) can no longer provide care satisfactorily. As opposed to the earlier categories, wherein care giver age/health was an issue, in this category the physical/mental status/health of the person with developmental disabilities is the key factor.
- C6. **There has been a death in the family or other family crisis, requiring additional support.** This is appropriate in cases where, although the care giver and person with developmental disabilities have not been directly affected, the death in the family (especially of a care giver spouse or other family member who may have assisted in providing care) or divorce or other crisis has the effect of requiring a need for additional support:
- C7. **Person has a care giver(s) who would be unable to work if services are not provided.** This is appropriate in situations where the care giver(s) must work to provide income to pay the rent, etc. If services are not provided, the care giver(s) would have to remain at home to provide support, and effectively be unable to continue working.
- C8. **Person or care giver expresses a need for alternative living arrangements within a year.** This category is appropriate for situations where the person with developmental disabilities or the care giver express a desire for alternative living arrangements within a year (e.g., person wants to move out of the home to be on her/his own or in a group setting, or care giver wants to move to another setting that require alternative plans for the person with a developmental disability).
- C9. **Person has graduated or left school in the past 10 years or is graduating within the next three years from school, and needs supports.** This category is appropriate for persons who have (or will shortly) graduate from school and will need day supports (i.e., there are no other employment or other day support options available/planned).

- C10. **Person is living in an inappropriate place, awaiting proper place.** This is appropriate for persons who are in a placement that is clearly inappropriate for them, but in which they can continue to reside for the short term (less than a year) until a proper placement is found. In the emergency category this placement would be intolerable - in this category the placement is inappropriate. An example may be where the roommate combination is inappropriate, etc.
- C11. **Person moved from another state where they were receiving services (residential, day and/or home-based supports).** This is appropriate for persons who were receiving services in the state in which they formerly resided but have now moved to Illinois and wish to continue receiving these services.
- C12. **State plans to assist this person in moving in the next year.** This is appropriate for persons in situations which the state has deemed inappropriate/unacceptable for whatever reason and the state has planned to move the person from this placement within the next year. This would include, but not be limited to individuals who the state plans to move out of state-operated or private ICF/DD, nursing home, or other congregate settings during the next year.
- C13. **Person is losing eligibility for Department of Children and Family Services (DCFS) support in the next year.** This is appropriate for persons who currently are receiving funding, services, or a placement through DCFS but for whom this eligibility will be terminating within the next year due to the age of the individual.
- C14. **Person is losing eligibility for Early, Periodic Screening, Diagnosis and Treatment (EPSDT) support in the next year.** This is appropriate for persons who currently are receiving funding, or services through the EPSDT program (well-child screening and services for individuals under age 21 including those who are parents), but for whom this eligibility will be terminating within the next year primarily due to the age of the individual.
- C15. **Person is losing eligibility for Intermediate Care Facility for People with Developmental Disabilities (ICF/DD) support in the next year.** This is appropriate for persons who currently are receiving funding for a placement through ICF/DD, but for whom this eligibility will be terminating within the next year due primarily to a change in resources of the individual or a change in the level of care needs of the individual.
- C16. **Person is losing eligibility for Medically Fragile/Technology Dependent Children's Waiver supports in the next year.** This is appropriate for persons currently receiving funding for a placement through this waiver, but for whom this eligibility will be terminating within the next year due to the age of the individual.

- C17. **Person is residing in an out-of-home residential setting and is losing funding from the Public School system in the next year.** This is appropriate for persons who currently are receiving funding for a placement through the public school system, but for whom funding for this placement will be terminating within the next year due to the age of the individual.
- C18. **Person is losing eligibility for Individual Care Grant supports through the mental health system in the next year.** This is appropriate for persons who currently are receiving funding for a service or a placement, but for whom this eligibility will be terminating within the next year due to the age of the individual.
- C19. **Person is leaving jail, prison, or other criminal justice setting in the next year.** This is appropriate for persons who will be released from a criminal justice setting within the next year and for whom supports must be found.
- C20. **Person wants to leave the current setting in the next year.** This is appropriate for persons who have expressed a desire to move from their current residential setting in the next year.
- C21. **Person needs services within the next year for some other reason.** Please specify for what reason the individual needs services in the next year.

PUNS Form Completion Manual (N-01-01-06)

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,

vs.

JULIE HAMOS, et al.,

Defendants.

No. 05 C 4331

Chief Judge Holderman
Magistrate Judge Cole

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.

Department of Human Services (DHS)/Division of Developmental Disabilities (DDD) Children 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 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 of serious harm.

Case 1 - Example of imminent risk of 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 of 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 with 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. 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.

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