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Advocacy Guide

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A COFAR Advocacy Guide to Families and Guardians

This guide is intended to help you advocate for the best possible care and services for your wards or family members with intellectual disabilities. It's designed to help if you are feeling overwhelmed by the complexities of the DDS system in Massachusetts, or if you simply want more information about matters relating to the care of your family member or ward in the system. You will find both tips and advice on, and summaries of, applicable DDS and federal regulations on care and services, eligibility issues, Individual Support Plans, guardianship, and other issues.

COFAR has constructed this guide as part of our mission of providing advocacy information and advice to families and guardians of those with intellectual disabilities, wherever they may live. We've divided up this guide into the following sections:

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We welcome your questions and any feedback or suggestions you might have.

Part 1: Advocating Effectively on Behalf of Your Family Members and Wards

This first section of our Advocacy Guide is intended to give you tips and insights on advocating for the best possible care for your family members or wards with intellectual disabilities. Additional sections will provide you with information on your rights under the Department of Developmental Services system, as well as procedures, regulations, and policies that are important to know.

To use this guide, you don't have to read it all through at one sitting. If you are faced with a specific problem, try skimming through each part, noting the headings as you go, and focusing on those areas that seem most relevant to you. If you have any questions, feel free to contact us.

This first section of this guide is meant to be read in conjunction with Sections on **Protections for Ricci Class Members and non-Class Members**. It should also be read in conjunction with Sections 4 and 5 on **Individual Support Plans and Guardianship**.

It is intended for family members and guardians of persons who have been determined to be eligible for DDS services and supports. If your ward or family member has not yet been determined to be eligible, please link to Section 2 on **Getting Services (Determining Your Eligibility)**.

NOTE: *There are numerous DDS regulations cited throughout this guide in order to best assist you in your advocacy efforts. Be aware, however, that regulations are subject to change by DDS and regulatory citations can become outdated. We will strive to keep this guide as up to date as possible.*

The full text of all DDS regulations can be found on the DDS's website at www.mass.gov/dds/.

Boosting Your Effectiveness as an Advocate

There are several ways of boosting your effectiveness in advocating on behalf of your family members and wards. The following are some methods we recommend:

Participate in, and make use of, the Individual Support Plan Process

The ISP Process is a critical component of the delivery of services and supports and functions as a contract between the family member or guardian and the

DDS. If the terms of your family member's or ward's ISP are not being met, there is a clear-cut process for appeal.

Be Pro-Active and Speak Out

Don't be afraid to speak directly to staff people or officials, or to telephone or write letters on behalf of your family member or ward if you feel there are problems involving his or her care and services.

Don't get stuck in dead-end dialogues with people who aren't doing anything for you. Go up the chain of command.

In a community residence, contact the house director or supervisor and your service coordinator. Your service coordinator is your advocate in addition to coordinating the services your ward or family member receives.

If the problem is in a state facility, contact the unit director and finally the facility director. If you're not sure who the unit director is, it is fine to contact the facility director.

If your problem still isn't resolved, contact your service coordinator, DDS area office and, if not resolved there, the DDS regional director and the Commissioner. Other contacts in these situations include COFAR and your state representative or state senator.

Whomever you contact, whether by phone, mail or email, be sure you state your claim clearly and concisely. Try to be factual, not accusatory. Keep correspondence to one page if possible.

Don't be afraid to pick up the telephone or write:

If you are writing, use certified mail, especially with the DDS. Email is effective as well, but may not have the legal impact of certified mail.

Keep documentation

Make every effort to keep good documentation. Be sure you document who you spoke with (aide's name, phone number) and date/time you called. If you make a phone call, it's a good idea to follow up in writing on your understanding of what transpired, to avoid any misunderstanding and also to have a record.

If abuse has occurred:

Contact the Disabled Persons Protection Commission at www.mass.gov/dppc/. (Click on Additional Resources for further contact information on the DPPC). The DPPC is unfortunately under-funded. COFAR has long advocated for legislation to transfer the DDS's investigative resources to the DPPC, which is an independent agency.

Know the regulations

DDS regulations govern the delivery of services and to persons with intellectual disabilities and make a number of specific statements about the manner in which those services and supports are delivered. If you believe that your family member or ward is receiving substandard care, you can make a determination as to whether any regulations are being violated. Once you have documented specific violations, you will be in a strong position to advocate for change. Below are key excerpts from DDS regulations governing supports and services. The full text of these regulations can be found on the DDS's website at www.mass.gov/dds/.

Standards to Promote Dignity: 115 CMR 5.00

5.03 General Principles

Services and supports are to be designed to provide “meaningful assistance to the individual in acquiring and maintaining those physical, mental, and social skills which enable the individual to cope most effectively with the demands of his or her own person and environment.” Services and supports are to be provided in a manner that promotes:

- Human dignity
- Humane and adequate care and treatment
- Self-determination to the person's fullest capacity
- Least restrictive care
- The opportunity to undergo typical developmental experiences, provided that the person's safety and well-being are not unreasonably jeopardized
- The opportunity to engage in activities and styles of living which encourage and maintain the integration of the person in the community through individualized social and physical environments.

5.04 Other Rights of Individuals:

Individuals served by providers must have, in addition to the rights specified elsewhere in 115 CMR or in applicable state or federal laws or judicial decrees, the following rights:

- The right to communicate, including:

The right to have reasonable access to a telephone and opportunities to make and receive confidential calls...

The right to unrestricted mailing privileges

- The right to be protected from private and commercial exploitation including: the right not to be exposed to public view by photograph, film, videotape, interview, or other means unless prior written consent of the individual or guardian is obtained...
- The right to be visited and to visit others under circumstances that are conducive to friendships and relationships...
- The right to enjoy basic goods and services without threat of denial or delay for any purpose by providers...including a “nutritionally sound diet of wholesome and appetizing food.”
- The right to a reasonable expectation of privacy....
- The right to decline any service or support.

5.05: Mistreatment:

No provider subject to 115 CMR 5.03 through 5.14 shall mistreat an individual or permit the mistreatment of an individual by persons in its employ or subject to its direction. Mistreatment includes any intentional or negligent action or omission which exposes an individual to a serious risk of physical or emotional harm. Mistreatment includes, but is not limited to:

- Corporal punishment or any other unreasonable use or degree of force or threat of force not necessary to protect the individual or another person from bodily harm;
- Infliction of mental or verbal abuse, such as screaming, name-calling, or any other activity which is damaging to the individual's self-respect;
- Incitement or encouragement of individuals or others to mistreat an individual;
- Transfer or the threat of transfer of an individual for punitive reasons;
- Termination of services or supports or threat of termination of services or supports for punitive reasons;
- Any act in retaliation against an individual for reporting any violation of the Department's regulations;

- The use of any physical, mechanical, or chemical restraint as punishment, for the convenience of staff, or otherwise in violation of 115 CMR 5.11 (restraint);
- Sexual abuse of an individual;
- Intentional failure to obtain or render medical services; and
- Any act in violation of 115 CMR 5.00.

Citing the Regulations

If you have made a determination that there has been a violation of the regulations in the care of your family member or ward, it's important to cite the specific regulation(s) involved in your correspondence to DDS, the DPPC, your legislator, or other contacts that you make. Let's say, for example, that you believe your son has been subjected to harassment in a group home by other residents and that you have been unable to get this problem corrected. You may decide to write a letter to the director of your DDS area office. You might cite the applicable regulations as follows:

“The instances cited of harassment of my son appear to be violations of the DDS’s Standard to Promote Dignity (115 CMR 5.00), in particular 115 CMR 5.05 (b): Infliction of mental or verbal abuse, such as screaming, name-calling, or any other activity which is damaging to the individual's self-respect.”

Citing the regulations in cases such as this one requires the DDS or whomever you have contacted to focus on the standard you claim has been violated and to take action.

Your letter may also be more effective if you are able to document violations of your family member's or ward's Individual Support Plan.

Part 2: Getting Services (Determining Your Eligibility)

This second Section of this Advocacy Guide is intended for persons who have wards or family members who they believe may have an intellectual disability, but who are not currently receiving residential care or services from the Department of Developmental Services.

Determining your eligibility for supports and services:

If your family member or ward is not currently receiving DDS care or services and you believe help is needed from DDS, the first step you must take is to determine your family member or ward's eligibility for those services.

In order to be determined eligible, your family member or ward must fit the DDS's definition of intellectual disability under the regulations.

Know the DDS Regulations

The DDS regulations define **intellectual disability** (115 CMR 2.01) as “**significantly sub-average intellectual functioning** existing concurrently and related to **significant limitations in adaptive functioning**. Mental retardation manifests before age 18.”

Significantly sub-average intellectual functioning is defined as an intelligence test score of 70 or below “as determined from the findings of assessment using valid and comprehensive, individual measures of intelligence that are administered in standardized formats and interpreted by qualified practitioners.”

Significant limitations in adaptive functioning are defined as scores on an adaptive behavior test that are significantly below average in independent living, cognitive, communication and other skills.

NOTE: *In order to determine whether your ward or family member meets the criteria under these definitions, it is important to have him or her examined by a licensed psychologist, preferably one who has experience in professional testing. If you are seeking to determine eligibility for a child, you may be able to obtain free testing from a psychologist in the public school system in your community.*

DDS Services

A ward or client who fits the definition of intellectual disability may then be eligible for a range of supports and services, including the following:

- **Community Residential**

These are both state and vendor-operated community-based group home settings, which provide care, supervision, basic life skills and community living skills training.

- **Facility Supports**

This is care provided in state-operated developmental centers that are certified by the federal government as intermediate care facilities for the developmentally disabled (ICF/DD). A succession of administrations has attempted to close as many as four of six remaining ICFs/DD in Massachusetts and has restricted admissions to them. COFAR opposes the closures of these facilities.

- **Individual Supports**

Individual Supports consist of activities to enable individuals to live as independently as possible in the community. Individual supports include help with food shopping, cooking, banking, and housekeeping.

- **Community Day Supports**

Community Day supports help individuals to build and maintain their ability to participate in community activities by focusing on important skill areas that include communication, self-care, relationship building and community involvement.

- **Employment Supports**

Employment Supports provide supervision, training, and/or transportation that enable individuals to get paid jobs.

- **Family Support services**

These are supplemental supports that help families care for intellectually disabled persons at home. They include individual and/or family education and training, support groups, family support coordination, supports planning, supports for community participation, outreach and education, and respite.

- **Respite**

This is short-term, out-of-home care for individuals with intellectual disabilities. It allows parents and other primary caregivers to handle personal matters, emergencies, or take a break.

Before starting the application process for DDS services, you should understand that DDS regulations divide eligibility for services into four categories: 1) General Eligibility, 2) Special Eligibility, 3) Child Eligibility for Family Supports, and 4) eligibility based on a "Prioritization of Supports."

The following is an explanation of each eligibility category. ***You will want to determine which category or categories your family member fits:***

1) General Eligibility (115 CMR 6.04)

The General Eligibility category applies to persons: Who are 18 or older; who are “domiciled” in the State of Massachusetts; and who fit the definition of intellectual disability (see above)

2) Special Eligibility (115 CMR 6.05)

This category applies to persons who are class members of the Ricci v. Okin litigation in Massachusetts. This landmark lawsuit established standards and requirements for lifetime services and supports for people living in certain state Intermediate Care Facilities facilities for persons with intellectual disabilities (ICFs/DD). If you are a class member, you are automatically eligible for comprehensive supports and services. [For more information on services available under this category, link to Section 3 of this Guide: **Protections for Ricci Class Members and non-Class Members.**]

3) Child Eligibility for Family Supports (115 CMR 6.06)

Persons younger than 18 may be eligible for certain family support services provided they:

1. Are domiciled in Massachusetts

2. Have a “verified diagnosis of intellectual disability or a closely related developmental condition, or with respect to persons from birth to age five a developmental delay. “ A Closely Related developmental Condition includes such things as Autistic Disorder, Down Syndrome, Williams Syndrome, Cerebral Palsy, Fetal Alcohol Syndrome, and other developmental disorders as determined by DDS (See Regulation 115 CMR 2.01).

Note: Most services for children under the age of 22 are provided under Special Education programs funded through local school districts, or from agencies such as the Department of Children and Families. More information about Special Education services can be found later in this section.

4) Prioritization of Supports (115 CMR 6.07)

This fourth category of eligibility applies to all non-Ricci Class Members. The regulation states that supports or services for those who are not Class Members are “subject to the availability of resources.” This can mean that supports and services for persons who are not class members can be reduced or eliminated in times of budget cutbacks.

COFAR has found that due to a general lack of available resources, DDS has, in recent years, been unable to provide requested supports and services in a timely manner to many people who request them. DDS does not admit to maintaining a waiting list for services, but it is believed thousands of families in Massachusetts are waiting at any given time for months or longer for community residential and other services.

This is a problem that we believe is exacerbated by the policy of successive administrations in recent years to close ICFs/DD in the state. Since most of the residents of those centers are Ricci class members, they take priority for supports and services over other persons waiting for those supports in the DDS system.

For non-Ricci class members, DDS Regulation 115 CMR 6.07 establishes priorities for providing supports and services. Those priorities are based on an assessment by DDS of the individual’s functional impairment, cognitive needs, behavioral and medical needs, and available “generic resources,” and “natural supports.” COFAR has objected to the introduction of “generic resources” into the regulation, arguing it isn’t defined and could give DDS wide latitude to deny services to families.

The priority system for providing services to adults who are non-Ricci Class Members is based on “the severity of the individual’s needs.” That criteria isn’t further defined either.

In addition, 24-hour Community Residential supports and other specific community-based services are provided under the following priority system [115 CMR 6.07(3)]:

1. The supports are deemed necessary to protect the health and safety of the individual or others.
2. The supports are deemed necessary to meet one or more of the individual’s needs in their Individual Support Plan.

You can appeal DDS’s decisions regarding the prioritization of services in your case, under the DDS

appeal regulations [115 CMR 6.30 through 6.34]. For information on filing appeals, link to Section 4 of this Advocacy Guide on **Individual Support Plans**.

The DDS application process

Under DDS regulations (115 CMR 6.02), you can apply to any DDS office or provider by filling out an application form. You can also obtain applications online at www.mass.gov/dds/.

The Regional Eligibility Team for the DDS's geographic region in which the applicant resides makes the determination of eligibility for supports in all cases. Applicants who are found ineligible may re-apply after one year "if the application is supported by new or additional information not previously submitted to the Department." The family of a child who experiences the onset of a developmental disability that is "distinct from the original delay or disability prompting the initial application" may re-apply at any time prior to the child reaching age 18.

Following the receipt of an application, the Regional Eligibility Team will inform the applicant regarding the following:

- the criteria for eligibility for DDS services
- the procedures for eligibility determination
- the system of prioritization for receipt of supports based upon need, funding and availability
- DDS's authority to charge for services, including costs associated with a determination of eligibility
- DDS's authority to require information about the applicant's and his or her family's needs, income, legal status, and resources before providing, purchasing, or arranging services
- the right of the applicant to appeal a determination of ineligibility under 115 CMR 6.30 through 6.34; and
- the person's obligation, as a condition of eligibility, to consent to DDS obtaining information from current and previous service providers and other state agencies.

Under the regulations, DDS has 60 days to make an eligibility determination and notify the guardian or family member of its decision (115 CMR 6.03).

You can appeal all DDS determinations about Eligibility, under the DDS appeal regulations (115 CMR 6.30 to 6.34). (Link to our Advocacy Guide Section 4 on **Individual Support Planning—the Appeals Process**.)

Special Education services

If your ward or family member is under age 22, he or she may be eligible for Special Education Services, which are specified under both state and federal law.

Special Education services are required to be provided for free by your school district and must be tailored to meet your ward or family member's needs. More information about Special Education services, eligibility requirements, Individual Education Plans and other related issues can be found on the state Department of Education website at www.doe.mass.edu/sped/ , or call 781-338-3000.

Turning 22

Parents and guardians should be aware that a child's eligibility for Special Education services ends when the child graduates from high school or when he or she reaches the age of 22.

As your child reaches his or her teen years, you should begin to work with Special Education personnel at your school to develop a plan to carry out the transition to DDS services. This is sometimes referred to as a Chapter 688 referral for continuing services. Chapter 688 referrals are normally made to DDS or to the Massachusetts Rehabilitation Commission or the Department of Mental Health. Families should also apply at this time to the Social Security Administration for an eligibility determination for Supplementary Security Income (SSI).

NOTE: *Become familiar with the adult services in your area long before your child reaches graduation or turns 22. Involve yourself with a parent group and/or COFAR.*

For further information on Turning 22 issues, contact DDS or:

The Massachusetts Department of Elementary and Secondary Education, Special Education Planning and Policy: (781) 388-3375

The Massachusetts Rehabilitation Commission: 1-800-245-6543 (Voice/TDD) or (617) 204-3600.

Part 3: Protections for Ricci Class Members and non-Class Members

This third section of this Advocacy Guide is intended to give family members and guardians insight into the protections that state and federal regulations provide to ensure adequate supports and services for persons within the DDS system. It is intended for family members and guardians of persons who have been determined to be eligible for DDS services. If your ward or family member has not yet been determined to be eligible, please see Section 2 on **Getting Services (Determining Your Eligibility)**.

This section is also intended to supplement Section 1 on **Advocating Effectively on Behalf of Your Family Members and Wards**. It should also be read in conjunction with Sections 4 and 5 on **Individual Support Plans and Guardianship**.

Protections for persons with Ricci Class Member status:

If your ward or family member is a Class Member in the Ricci v. Okin lawsuit, he or she enjoys some of the most comprehensive protections for supports and services available under the DDS system.

In 1993, U.S. District Court Judge Joseph Tauro disengaged from his oversight of the then Department of Mental Retardation (now the Department of Developmental Services), stemming from Ricci v. Okin. The landmark lawsuit brought about significant improvements in the care of persons with intellectual disabilities throughout the DDS system in Massachusetts, and, in particular, in the remaining large, state-operated facilities, now known as Intermediate Care Facilities (ICFs/DD). These facilities house some of the state's most severely and profoundly intellectually disabled citizens.

In disengaging from the case, Tauro issued an order that resulted in lasting protections for Ricci Class Members. According to a DDS Class Member handbook, Judge Tauro's 1993 order applies to anyone identified as a class member in DDS's Class Identification List as of April 30, 1993, **regardless of where the person now lives**. Those listed are people who were residents of the following facilities on or after the following dates: Belchertown (2/7/72); Dever (12/17/75); Fernald (7/23/74); Monson (9/17/75); and Wrentham 12/4/75). These are the dates the original lawsuits were filed.

DDS regulations further state that, after April 30, 1993, if someone has lived at the Fernald, Monson, Wrentham, Templeton, or Dever developmental centers for more than 30 consecutive days, or for more than 60 days during any twelve-month period, that person would also become a class member. (115 CMR 6.05)

Judge Tauro's order stated that each class member, **"on a lifetime basis,"** has a right to have the state **"substantially provide services" which are described in the person's Individual Support Plan (ISP).** The services include residential and day programs, recreational activities, medical, dental, psychological services, respite care, crisis intervention services, adaptive equipment, guardianship services, and transportation. Further, "sufficient and adequately trained personnel" must be available to substantially meet the needs set forth in each class member's ISP.

Under Tauro's order, any changes to the DDS regulations must leave in place at least the "substantial equivalent of the current definition of the ISP," the current "individualized nature" of the ISP, existence of an appeal process, and other protections. The state must also maintain and implement the basic principles of the ISP which include: 1) human dignity, 2) humane and adequate care and treatment, 3) self-determination to the person's fullest capacity, 4) least restrictive care, 5) the opportunity to undergo normal developmental experiences, provided that the person's safety and well-being are not unreasonably jeopardized, and 6) the opportunity to engage in activities and styles of living which encourage and maintain the integration of the person in the community through individualized social and physical environments.

And Tauro's order stipulated that the DDS must not approve a transfer of any class member out of a state facility into the community... "until and unless the Superintendent of the transferring school...certifies that the individual to be transferred will receive equal or better services to meet their needs in the new location, and that all ISP-recommended services for the individual's current needs as identified in the ISP are available at the new location."

NOTE: On the basis of Judge Tauro's 1993 order, COFAR has opposed attempts by the DDS since 2003 to shut down the Fernald Developmental Center in Waltham and thee of the other remaining ICFs/DD. For the latest information on the status of Ricci v. Okin and efforts to prevent the shutdown of remaining state facilities, read The COFAR Voice in Newsletters on our website and visit our blogsite.

These protections for Ricci Class Members are now codified in DDS regulation 115 CMR 6.05: Special Eligibility.

The regulation defines Special Eligibility as applying to anyone listed as a Ricci Class Member (see above), and states that Class Members are entitled to:

- an assessment of eligibility
- a designation of area of service
- assignment of a service coordinator

- an Individual Support Plan (ISP) and substantial provision of the services or supports recommended in his or her ISP for so long as such services or supports are needed and authorized by the individual and his or her guardians; and
- the least restrictive, most typical, appropriate residential environment, together with the most appropriate treatment, training and support services suited to that person's individual needs.

Protections for persons who are not Ricci Class Members:

Persons under DDS care who are not Ricci Class Members are subject to DDS regulation 115 CMR 6.07:

Prioritization of supports, which provides that their services are subject to the availability of resources, as determined by the Legislature. This can mean that those services can be reduced in times of budget cutbacks. Nevertheless, both state and federal regulations still provide recourse to non-Class Members who are receiving substandard care or cannot get care.

For instance, non-Ricci Class Members are entitled, just as all persons in the DDS system are, to the protections under Standards to Promote Dignity: 115 CMR 5.00 (Click on Part 1 of this Advocacy Guide—Advocating Effectively on Behalf of Your Family Members.)

If a non-Class Member's services have been reduced so that he or she is no longer receiving "humane and adequate care and treatment," or he or she has lost the opportunity "to undergo normal developmental experiences" or the opportunity to maintain or integrate ties with the community, that might be grounds to allege a violation of DDS regulations.

In addition to the protections given to individual Class Members, the State must maintain compliance with federal obligations regarding services both in state-operated Intermediate Care Facilities (ICFs/DD) and in the community. Violations of these regulations can also provide a basis for initiating a complaint process with DDS.

Know the federal statutes and regulations

Federal ICF/DD statute and regulations

ICFs/DD in Massachusetts receive federal Medicaid Funding authorized by Title XIX of the Social Security Act [42 U.S.C., section 1396d(a)(15)]. The federal law and regulations require that ICFs/DD provide "active

treatment,” including occupational therapy, speech therapy and physical therapy. DDS permits only limited admissions to the state’s ICF/DD facilities.

Federal community-based care statute and regulations

Community-based care is provided under the Home and Community Based Waiver to Title XIX of the Social Security Act. Under the Home and Community-based waiver program [42 U.S.C., section 1915(c)], states may offer an array of home and community-based services. Among the federal requirements to states such as Massachusetts that participate in the Home and Community Based Waiver program is that services be provided “with reasonable promptness” [42 U.S.C., section 1396a(a)(8)].

ICFs/MR are periodically investigated for compliance with federal standards by the state Department of Public Health. Community programs are reviewed periodically by DDS, through its Quality Enhancement licensure and certification process. If you are receiving substandard community-based care, you may be able to cite violations of applicable federal regulations.

NOTE: DDS and some advocacy organizations have taken the position that a U.S. Supreme Court ruling [Olmstead v. L.C., 527 US 581 (1999)] justifies the closing or consolidation of all remaining state ICF/DD facilities. Starting in 2003, the Commonwealth began taking steps to close the Fernald Developmental Center in Waltham and four other remaining state facilities and to transfer the facility residents to the Wrentham Developmental Center and to community-based group homes.

DDS contends that this privatization effort is justified because the Supreme Court ruled in the Olmstead case that facility-based care discriminates against persons with intellectual disabilities. COFAR, however, has argued, in a brief filed jointly in federal court with the national VOR, that the Olmstead case specifically authorized the use of ICFs/DD as appropriate centers of treatment for those persons who want and need them.

Congress also provided that persons with intellectual and other developmental disabilities have the freedom to choose whether to receive services in a state-operated facility or in a community-based residence under the Home and Community Based Waiver [42 U.S.C. section 1396n(c)(2)(C)]. COFAR has strongly opposed efforts to close the ICF/DD facilities because comparable services are not currently available in the community-based system.

Boulet and Rolland Class member protections

Two federal court cases in addition to the Ricci case have resulted in additional services to persons in the Massachusetts DDS system who aren't Ricci Class Members:

1. In **Rolland v. Cellucci**, plaintiffs with intellectual disabilities were unnecessarily admitted to, and inappropriately confined in, nursing homes regardless of their preferences or DDS's clinical review teams. In the nursing homes, they were not provided with even minimally adequate training, habilitation, or support services. In this case, DDS was alleged to have violated federal regulations by failing to provide appropriate Medicaid habilitative services to all eligible class members in accord with federal Medicaid law and Title XIX of the Social Security Act.

From Fiscal Year 2001 to Fiscal Year 2007, DDS was required under a settlement of the case to move hundreds of people who wished to leave nursing homes into community-based residential care. The settlement, however, resulted in controversy when DDS chose to interpret it to authorize the removal of residents of the Seven Hills Pediatric Center, an intensive care rehabilitation center for children with disabilities. Parents and guardians of those residents have fought to keep their children in the Center. (See www.avertrollandtragedy.org)

2. In **Boulet v. Cellucci**, DDS acknowledged that as of July 2000, there were 2,437 persons with Intellectual disabilities and eligible for Medicaid on a waiting list for care, including 1,961 individuals waiting for state-funded, out-of-home placements; 210 waiting for non-residential services; and 266 waiting for both of those.

Under the July 2000 settlement, DDS agreed to request \$85 million in additional appropriations to provide for 1,250 new state funded out-of-home placements and interim services for the plaintiffs from Fiscal Year 2002 through Fiscal Year 2006. The court ruled that the state had violated its obligation under the federal Medicaid statute that assistance be provided with reasonable promptness. Applicants for care had been kept on a waiting list for long period of time when residential settings were available.

Protections for state facility residents facing transfers to other locations

For Ricci Class Members and others in the DDS system who are facing transfers from their DDS-funded residences (in some cases involuntarily), DDS regulations provide some protections against a loss of services following the transfers. The regulations also allow for appeals of the transfers themselves.

Ricci Class Members are further protected Under U.S. District Judge Tauro's disengagement order in the Ricci v. Okin case that DDS must not approve a transfer to the community unless the director of the state facility or the DDS Regional Director certifies that the person will receive equal or better services in the new location, and that the ISP-recommended services are available there (see above).

NOTE: *The question of whether equal or better services exists in the community was key to litigation before U.S. District Court Judge Joseph Tauro. In August 2007, Tauro found that the state has engaged in a "systemic failure to provide a compliant ISP process" because of its "global policy judgment" that the Fernald Developmental Center be closed. He ordered that Fernald be included as an option in residential placement choices for current Fernald residents. In October 2008, the U.S. First Circuit Court of Appeals overturned Tauro's order, saying he lacked jurisdiction to reopen the Ricci v. Okin case.*

In August 2010, guardians of some 20 remaining Fernald residents invoked a state statute and DDS regulations that permit administrative appeals of transfers of their wards from one location to another.

For an explanation of these regulations, see Transfer Regulations under the Part 4 of this Advocacy Guide—the Individual Support Plan process.

Part 4: Individual Support Plans

This fourth section of this Advocacy Guide is intended to give family members and guardians detailed information on DDS policies and procedures regarding Individual Support Plans (ISPs). Understanding your rights and obligations regarding ISPs is critically important to you in advocating for the best possible care and services for your family members and wards in the DDS system.

This section is intended for family members and guardians of persons who have been determined to be eligible for DDS services. If your ward or family member has not yet been determined to be eligible, please link to Section 2 on **Getting Services (Determining Your Eligibility)**.

This section is also intended to supplement Section 1 on **Advocating Effectively on Behalf of Your Family Members and Wards**. It should also be read in conjunction with Section 3 on **Protections for Ricci Class Members and non-Class Members** and Section 5 on **Guardianship**.

Defining Individual Support Plans

Individual Support Plans (ISPs) are defined in the DDS regulations as a “written plan of services or supports for an individual, which is developed, implemented, reviewed, and modified according to the requirements“ of DDS regulations (115 CMR 2.01).

ISPs are critically important because they serve as legally binding contracts on DDS to provide the care and services enumerated in them. It is vital to understand what goes into the development of your family member or ward’s ISP, and how the ISP development and appeals process works.

Know the DDS Regulations

Knowing the DDS regulations regarding ISPs is fundamental to understanding your rights and obligations concerning them.

The regulations describe the ISP process as an ongoing one of “establishing **goals for individuals consistent with the outcomes** described in the **quality of life areas...**, and of **identifying supports and strategies** that will promote achievement of those goals” (115 CMR 6.20: Introduction to Individual Support Planning). More will be said below about the quality of life areas.

The regulations also note that “successful (ISP) support planning requires the greatest possible involvement of the individual, his or her family, guardian, and

designated representative, if any, the Department, and providers of supports to the individual.” Each participant, according to the regulations, is expected to have a “continuing commitment to learn about the individual and about his or her current goals and circumstances, and to support the individual in particular ways to realize those goals.”

In addition, 115 CMR 6.21(2) requires the DDS to “provide reasonable assistance and accommodations to enable the individual and other members of the ISP team to participate meaningfully in the development, review, and modification of the ISP.”

NOTE: Your own participation in the ISP process can be enhanced by developing a “wish list” beforehand of the most comprehensive and appropriate services and residential settings you would like your family member or ward to receive. Include your own goals for your family member or ward, and your preferences for day programs, nursing services, physical and occupational therapy, and other services that you believe would best help achieve those goals. Be sure to discuss your wish list with your service coordinator and others involved in the ISP process.

Assessments and Consultations

In developing the ISP, DDS must conduct “assessments and consultations” in order to establish agreed-upon goals for your family member or ward and strategies for reaching those goals (CMR 6.22). Among the assessments that are required by the regulations to be reviewed by the service coordinator on an annual basis are:

- An assessment of the type of supports needed by the person
- An assessment of the person’s ability to make informed decisions about his or her financial and personal affairs; and
- An assessment of the person’s financial status and eligibility for services or benefits from other entities such as the Social Security Administration [115 CMR 6.22 (3)].

The ISP Timetables

The timetables for ISP meetings and the development of ISPs themselves, as well as the timetables for reviews, approvals, updates, modifications and appeals of the ISP are spelled out in the DDS regulations. The following is intended to help you sort through these timetables so that you can better understand your rights and obligations and DDS’s obligations concerning them. If there are delays in the scheduling or processing of your ward’s or family member’s ISP, the following timetable may be helpful to you to be able to determine whether a violation of DDS regulations was involved.

The ISP Meeting

The ISP process starts with the ISP Meeting, which is normally set up by your ward's or family member's service coordinator. The regulations [115 CMR 6.23 (1)] state that during the Meeting, the members of the ISP team must develop a plan that describes **"goals for the individual as well as services needed to reach those goals."** The plan must describe the availability of those services and must include strategies for meeting those needs of the person for which services may not be available.

Quality of Life Areas

The regulations [115 CMR 6.23 (2)] list six quality of life areas, within which, the services in the ISP must promote positive outcomes. The quality of life areas are: **1) Rights and Dignity, 2) Individual Control, 3) Community Membership, 4) Relationships, 5) Personal Growth and Accomplishments, and 6) Personal Well-Being (Health Safety and Economic Security).** (These areas are similar to the six Principles listed under the DDS's Standards to Promote Dignity (115 CMR 5.03), which are discussed in Section 1 of this Advocacy Guide: **Advocating Effectively on Behalf of Your Family Members and Wards.**)

Under **Personal Well-Being (Health, Safety, and Economic Security)**, as an example, the regulations state that the ISP must promote an outcome that ensures that:

"the individual receives health care and related services which are sufficient and appropriate to optimize the individual's health and well-being; he or she lives and works in environments that are safe, secure, and are adapted if necessary to meet the individual's needs, and safeguards are in place to respond to emergencies and threats to the individual's health or safety; [and] he or she has sufficient economic resources to meet his or her needs."

Components of the ISP Meeting

NOTE: *Keep the following two checklists in mind when you attend your ISP Meeting:*

ISP Checklist 1: The regulations [6.23(4)] stipulate that the ISP Meeting must cover the following areas at a minimum:

- Discussion of, and identification of, your family member's or ward's goals and desires in terms of the quality of life areas identified under 115 CMR 6.23(2) [see Quality of Life Areas above];
- Discussion of experiences and events in recent years that may affect the person's immediate future, general health, safety, or long-term goals; and
- Development of a "support agreement."

ISP Checklist 2: The ISP or "support agreement" must include following:

- Specific goals for each area referred to above **[ask that the goals on your wish list be included in the ISP support agreement];**
- Strategies and least restrictive services to reach these goals **[ask that services on your wish list be included in the ISP support agreement];**
 - The expected duration and frequency of the services **[ask that any specific statements about these on your wish list be included in the ISP support agreement];**
- Criteria to be used in evaluating the effectiveness of the services;
- Any unmet needs for services and the strategies which will be utilized to address those needs;
- The team members' responsibilities for monitoring and reporting on the implementation of the support agreement as well as the format and frequency of such monitoring and reporting; and
- The date of the next review of the ISP, which can be no later than one year from the date of the ISP meeting.

NOTE: *Strategies and services in the support agreement may include instruction in skills related to health and safety, self-care, communication, home living, work, leisure, social interactions, community use, self-direction and functional academics, provision of medical, dental and specialty services such as physical or occupational therapy, psychiatric or psychological services, and legal or advocacy services, and the party responsible for their provision or implementation.*

Timing of the ISP Meeting

The regulations state that your service coordinator must convene the Meeting (see above) to develop the ISP for your ward or family member within 60 days after he or she begins receiving services under the DDS system. Every two years, a meeting must be held to develop a new ISP [115 6.23 (3)]. **Each ISP is also reviewed annually (see below).**

NOTE: *Bring your wish list and the ISP checklists above with you to the ISP meeting. Take notes, if possible, on what has been discussed. Make sure that all the major items on your wish list and the checklists are discussed to your satisfaction. If you believe anything has been left out, mention it to your service coordinator.*

Approval of the ISP

Within 30 days following the ISP Meeting, the ISP must be reviewed by the DDS area or facility director or designee. The area or facility director must either approve the document or disapprove it in part or in whole, and mail it to the individual, family, guardian, designated representative and providers [115 CMR 6.23(5)]. The service coordinator must notify the individual and family or guardian of their right to have a meeting with the service coordinator to explain the ISP **within 10 days** of receipt, and of their appeal rights under 115 CMR 6.30 through 6.34.

NOTE: *It is critically important when you receive the written ISP document to carefully and compare it with your wish list, your ISP checklists, and your notes from the ISP Meeting. The ISP should contain all of the assessments, goals, services, settings, and strategies that were agreed upon in the ISP Meeting. Once again, if anything is missing from the document, bring it up with your service coordinator.*

Should the area or facility director suggest changes to the ISP that significantly alter it, he or she must discuss the reasons for those changes with your service coordinator [115 CMR 6.23 (5)(b)]. Your service coordinator can also reconvene the ISP Meeting if the area or facility director has recommended changes that significantly alter the ISP.

Under 115 CMR 6.23 (5)(c), the ward or family member, his or her guardian, and any family members who participated in the development of the ISP will be **asked to sign the ISP or indicate their intent to appeal it** (see Appealing the ISP below). You will be deemed to have agreed to the plan unless an appeal is filed within 35 days of mailing of the ISP or of the explanatory meeting with the service coordinator [see above].

Annual review of ISPs

DDS's ISP regulations [115 CMR 6.24] require the ISP to be reviewed and updated on an annual basis. **Family members, guardians, or other team members may request more frequent reviews depending on the person's desires, goals, needs, and circumstances.**

During the ISP review, your service coordinator must provide any new or updated assessments of your ward or family member, and must review monitoring reports generated by the DDS and the provider. In consultation with the ward or family member, guardian, family members, and other team members, the service coordinator may make appropriate revisions to the ISP based on a review of the following:

- The satisfaction of the individual and others, including the individual's family and guardian;
- Progress toward achieving the goals identified in the ISP; and
- Any significant changes in the individual's circumstances or abilities;
- A determination "whether the goals identified in the ISP are consistent with the current desires and needs of the individual and whether the strategies and supports identified in the ISP continue to be the least restrictive, appropriate and available strategies and supports to promote achievement of those goals"; and
- The continued effectiveness and appropriateness of any authorizations given by the individual, his or her guardian, if any, a court, or other authority.

NOTE: In a stipulated agreement in December 2004 in federal court, DDS agreed that it would not use the annual ISP review to encourage or suggest transfers or relocations of persons in the DDS system from their residences. The agreement was part of litigation in the Ricci v. Okin case before U.S. District Court Judge Joseph Tauro. Judge Tauro, who had disengaged from the case in 1993, resumed hearings in 2004 after the Romney administration announced it intended to close remaining state Intermediate Care Facilities for the intellectually disabled (ICFs/DD) and ultimately transfer their residents to community-based care. According to the stipulation, DDS can only discuss transfers to new locations during the ISP modification process (see below). Regulatory protections under the ISP modification process for families and guardians whose wards are facing such transfers are discussed later in this section under Transfer Regulations.

ISP modifications

DDS regulations (115 CMR 6.25) spell out requirements and timetables for making changes at any time in your ward's or family member's ISP. The regulations note that these modifications can occur when there are such things as changes in the person's goals, the person's priority status for receiving supports, or a change in the person's DDS residence.

The ISP modification process

Under 115 CMR 6.25 (3), requests for ISP modifications must be addressed to the service coordinator and may be made by the ward or family member, the guardian, the service coordinator, a current service provider, or the person's designated representative.

After receiving a request for an ISP modification, the service coordinator must convene a meeting within 30 days to determine whether the modification should be made [115 CMR 6.25 (4)]. The meeting participants must be given at least 10 days notice of the meeting.

Within **ten days after a modification meeting**, the recommended modifications must be reviewed by the area or facility director or his or her designee, and approved or disapproved [115 CMR 6.25 (7)]. The service coordinator must notify the participants of the decision on the requested modification and of their right to appeal the modification under 115 CMR 6.63 or 115 CMR 6.30 through 6.34.

The Appeals Process

The DDS regulations (115 CMR 6.30 through 6.34) provide you with both a right and a procedure with which to appeal the following categories of DDS decisions regarding the ISP:

- Whether the goals identified in the ISP are consistent with and promote the outcomes described in the quality of life areas
- Whether the types of supports identified in the ISP are the least restrictive, appropriate and available supports to meet the goals stated in the ISP
- Whether the recommendation of the ISP team with regard to the individual's ability to make personal and financial decisions is consistent with the available evidence and whether the type of decision-making support recommended is consistent with the standards set forth at 115 CMR 5.07
- Whether the ISP was developed, reviewed, or modified in accordance with the procedures set forth in 115 CMR 6.20 through 6.25; and

- Whether the ISP is being implemented.

These same regulations also provide a right and a procedure with which to appeal other types of DDS decisions as well, including the following:

- Whether the decision of the Department as to the individual's eligibility for services is consistent with the standards and procedures stated in 115 CMR 6.01 through 6.10; and
- Whether the DDS's assignment of priority of need is consistent with the standards set forth in 115 CMR 6.07. [Link to our Advocacy Guide Section on **Getting Services (Determining Your Eligibility)** for a discussion of these eligibility regulations.]

NOTE: Appeals of DDS decisions to transfer your ward or family member from their current residence to a new location must be made under a separate regulation (115 CMR 6.63, Transfers: Special Requirements). See the discussion below under Transfer Regulations.

Initiating the Appeal

Under regulation 115 CMR 6.32, an appeal is initiated by notifying your Regional DDS Director in writing within 30 days after receipt of the ISP or the eligibility decision. An appeal that the ISP is not being implemented may be initiated at any time.

The Informal Conference

The Informal Conference represents an attempt to reach agreement on the disputed issues before the more time-consuming stage of the Fair Hearing (see below). Under 115 CMR 6.31(1), the Informal Conference must be held by the Regional Director or designee, or an ombudsperson designated by the DDS Commissioner, if requested by the appellant. **The Informal Conference must be held within 30 days of notification of the appeal.** Except for agreed-upon statements of fact, all other statements in the Informal Conference are not admissible during the Fair Hearing stage of the appeal or in subsequent court proceedings.

The Fair Hearing

The Fair Hearing represents a formal attempt to resolve the disputed issues, and its procedures resemble to those involved in an appeal to

the state Superior Court, which could be your next step in the process if the Fair Hearing decision is not satisfactory to you.

Under 115 CMR 6.33(2), you, as the appealing party, may petition the DDS Commissioner **within 30 days of the conclusion of the Informal Conference** for the Fair Hearing on your appeal. The DDS must hold a Fair Hearing **within 60 days of the filing of your appeal. Within 45 days of the conclusion of the Fair Hearing, the DDS Commissioner must issue a decision. The DDS area director then has 30 days to implement any changes ordered in the ISP or other matters under appeal.**

There are a number of provisions of the Fair Hearing regulation, which are important to know:

- During the Fair Hearing, you have the right to be represented by a person of your choosing, at your expense. If you are unrepresented at the hearing and desire assistance, or if for any other reason the DDS determines that appointment of an advocate would be in your ward's or family member's best interest, the hearing officer or the DDS must designate an advocate to assist in the appeal.
 - Both you and the DDS have the right to present any evidence relevant to the issues on appeal and have the right to call and examine witnesses.
 - You have the right, in accordance with 115 CMR 4.06, to examine all records held by the DDS pertaining to your ward or family member, including all records upon which the decisions under appeal were made.
 - The Fair Hearing is not open to the public, but the hearing officer may allow other persons to attend if he or she deems such attendance to be in the best interest of your ward or family member.
 - Following the Fair Hearing, the hearing officer must prepare and submit to the DDS Commissioner a recommended decision which shall include a summary of the evidence presented, findings of fact, proposed conclusions of law, the recommended decision, and the reasons for the decision.
 - The findings of fact in the recommended decision are binding on the DDS Commissioner. However, the Commissioner may modify the conclusions of law and decision "where the conclusions or decision are: in excess of the agency's statutory authority or jurisdiction; based on an error of law; arbitrary, capricious, an abuse of discretion, or otherwise not in accordance with law."
- **Within 45 days after the conclusion of the Fair Hearing, the DDS Commissioner must issue a decision, which will be the final decision of**

DDS on all issues. The decision must include a summary of the evidence presented, findings of fact, a decision on each of the issues appealed and the reasons for the decision, and a notice of the individual's right to appeal the decision to the Superior Court pursuant to M.G.L. c. 30A.

- The decision must be mailed to the individual, to all parties, to the Regional Director and to the individual's service coordinator.
- **Within 30 days of the decision**, the Regional Director must take action consistent with the findings and decision of DDS.

It is also important to know the following General Provisions about Fair Hearings (which are listed under 115 CMR 6.34):

- The standard of proof on all issues during a Fair Hearing is a preponderance of the evidence.
- The burden of proof is on you, the appellant, except that, with respect to appeals based on the restrictiveness of supports pursuant to 115 CMR 6.31(5), the burden of proof is on the party advocating the more restrictive alternative.
- If you are not satisfied by the final decision of the DDS, you are entitled to a judicial review of the decision, in accordance with M.G.L. c. 30A, § 14.

Transfer Regulations

As discussed under ISP Modifications above, DDS regulations specifically offer protections to you if DDS is proposing to transfer your ward or family member from his or her current residence.

The regulations (115 CMR 6.63: Transfers: Special Requirements) apply to any proposed modification to an ISP involving an individual moving from one DDS-funded residence to another. The regulations state that DDS must stop the transfer process if the guardian or other party objects to it. Under the regulations, the transfer can proceed only if the DDS prevails at an adjudicatory hearing.

The regulations state that all parties eligible to participate in ISP modification meetings must be given notice of a proposed transfer **at least 45 days prior to the date of the transfer (115 CMR 6.63(2))**. The written notice must include a statement explaining how the proposed move would result in improved services and supports and quality of life for the individual. It must also specify the location of the proposed home, include a statement that the parties may visit and examine the proposed home, and must invite the parties to consult with the service coordinator or other

designated staff regarding the advantages and disadvantages of the proposed transfer. (This consultation may take place as part of the ISP modification meeting.)

The written notice must further include a request for consent to the proposed transfer (consent to internal moves within a facility or residential location is not required); and include a statement of the rights of the parties established by 115 CMR 6.63, if applicable.

If any party to the ISP modification, other than a current or proposed provider of services and supports to the individual, files an objection to the proposed transfer, the transfer shall not occur unless:

- **The party withdraws the objection;**
- **The individual, if not under guardianship, consents to the transfer;**
- **The guardian consents to such transfer and the individual does not object; or**
- **DDS prevails at an adjudicatory proceeding held pursuant to 115 CMR 6.63(4).**

Any objection to the proposed transfer must be in writing, must contain a statement of the reasons for the objection, and must be addressed to the DDS Commissioner. Once an objection has been filed, DDS must file a request for an adjudicatory proceeding within the Division of Administrative Law Appeals **within 20 days of receiving the objection [115 CMR 6.63(4)]. The adjudicatory proceeding with the Division of Administrative Law Appeals is established by M.G.L. c. 7, § 4H.**

If DDS prevails at the adjudicatory proceeding, it must still **delay the proposed transfer for 20 calendar days** to enable the objecting party to appeal and seek a further stay of the transfer before a judge of the Superior Court in accordance with procedures and standards for such appeals established by M.G.L. c. 123B, § 3, and M.G.L. c. 30A. **If the Department does not prevail at the adjudicatory proceeding, it shall not proceed with the proposed transfer unless the administrative hearing officer's decision is reversed on appeal to a judge of the Superior Court.**

Part 5: Guardianship

This fifth section of this Advocacy Guide is intended to give family members and guardians detailed information on DDS policies and procedures regarding guardianship, its importance to the process of effective advocacy, and the steps needed to be taken to become a guardian.

This section is intended for family members and guardians of persons who have been determined to be eligible for DDS services. If your ward or family member has not yet been determined to be eligible, please link to Section 2 on **Getting Services (Determining Your Eligibility)**.

This section is also intended to supplement Section 1 on **Advocating Effectively on Behalf of Your Family Members and Wards**. It should also be read in conjunction with Section 3 on **Protections for Ricci Class Members and non-Class Members** and Section 4 on **Individual Support Planning (ISPs)**.

The Importance of Guardianship

Becoming a guardian of a person with intellectual disabilities can be critically important in ensuring that the person receives comprehensive care and services in the DDS system.

The appointment of a guardian legally fixes the status of the ward as a person incapable of caring for or managing their personal and financial affairs. The guardian's responsibility includes making decisions in the best interest of the ward and of no one else. The guardian is required to manage and dispose of all of the ward's personal property according to law in the best interest of the ward and to provide for the care of the ward.

If you are a family member of a person over 18 with an intellectual disability and you have not been appointed the person's guardian, you should strongly consider becoming their guardian if you believe they are unable to manage either their personal or financial affairs, or both.

There are a few key points to understand about guardianship and its importance to the care of persons in the DDS system:

- Once a person reaches the age of 18, that person is considered competent to manage his or her own personal and financial affairs.
- If the Department of Developmental Services determines that a person over 18 is not competent to manage his or her

affairs, the Department can seek to appoint a permanent or temporary guardian of the person.

- Even if you are a close relative of a person over 18 with intellectual disabilities, you will lose all decision-making rights with respect to that person if someone else is appointed his or her guardian.

Guardians have important legal rights in the care of their wards with intellectual disabilities. They are a party to the Individual Support Plan (ISP) process, and must give their approval to all ISPs and ISP modifications. If a guardian objects to an ISP or an ISP modification, he or she has the right to appeal it.

Know the Regulations

DDS regulations (115 CMR 5.07) specify the circumstances under which guardians can be appointed for persons with intellectual disabilities. The regulations recognize two broad types of guardianship services for persons with intellectual disabilities—**financial guardianship** and **personal guardianship**:

1. Financial guardianship:

Under 115 CMR 5.07(2), if an individual's ISP team has reason to believe that he or she is not competent make “informed decisions” with regard to financial affairs, the DDS or provider agency head must notify the person's nearest living relatives in writing, with an accompanying recommendation that steps be taken to protect the person's finances.

There are several levels of financial guardianship services that are specified in the regulations. Among the “least restrictive” are appointment of a “**representative payee**” for the person with an intellectual disability, or appointment of a “**co-signatory bank account**” or of a “**shared or delegated money-management plan.**” As representative payee of a person with an intellectual disability has control over such things as the person’s Social Security benefits and any personal funds accounts, which the person might have.

If DDS or a provider agency has reason to believe that a representative payee, co-signatory bank account, or a shared or delegated money management plan are inadequate to protect the individual “from a substantial and unreasonable risk to his or her property,” they can recommend a more restrictive guardianship service—specifically appointment of a **trustee, conservator, or guardian of the estate**. These more involved guardianship arrangements are normally recommended if the person has cash or assets easily converted into cash in excess of \$10,000.

A conservator, for instance, manages a ward's financial assets, such as bank accounts, paychecks or stocks and bonds. A conservator is also responsible for paying the ward's bills and debts out of the ward's assets; and a conservator is responsible for initiating or answering any legal actions that concern the debts owed by or to the ward.

2. Personal Guardianship

Under 115 CMR 5.07(3), if an individual's ISP team has reason to believe that an individual is not competent to "make informed decisions with regard to personal affairs," the DDS or provider agency head must notify the individual's nearest living relative in writing, with recommendation for services necessary to help the individual in decision-making. That recommendation might be to appoint a guardian if the DDS or provider agency head believes that less restrictive alternatives or services are inadequate to protect the person from an "unreasonable risk to his or her health and welfare." The regulations further state that the type of guardianship recommended must be "the narrowest and least restrictive necessary."

Appointment of a Guardian other than a Family Member

In cases in which the nearest living relative cannot be found or is incapable or unsuited for or not interested in becoming a guardian, the DDS or a provider agency head are authorized under DDS regulations to recruit a trustee, conservator, or a guardian, as they deem appropriate [115 CMR 5.07(4)]. Under this regulation, DDS or the provider agency head must attempt to ensure that:

- Temporary guardians are available to meet emergency situations;
- Persons requiring trustees, conservators or guardians are identified and the appropriate relatives are contacted;
- Suspected improprieties of a trustee, conservator, guardian, representative payee, or other fiduciary are reported to the probate court, the DDS, and other appropriate authorities; and
- The DDS or provider agency provide persons who ask with an explanation of trusteeship, conservatorship, and guardianship; and, refer those persons to appropriate legal assistance if they request or need it.

NOTE: *If you are contacted by DDS or a provider about the need for a guardian of a family member of yours, you should strongly consider seeking to become that person's guardian if you want a continued say in his or her care. If not, DDS may secure professional guardianship services from an attorney provider agency, which may or may not have the resources to ensure adequate and competent care for your family member.*

Becoming a Guardian

The process of becoming a guardian is governed by statute in Massachusetts (Massachusetts General Laws Chapter 201). The law (M.G.L. c. 201, Section 6A) states that the following persons or entities can be authorized to become the guardians of a person with an intellectual disability:

- A parent
- Two or more relatives or friends of the person
- A nonprofit Massachusetts corporation whose charter authorizes it to act as a guardian
- Any agency within the Executive Offices of Human Services or Educational Affairs

Any individual or organization that seeks to become a guardian of a person with an intellectual disability must file a petition to do so with the probate court. If you file such a petition, it must be accompanied by a report from a clinical team consisting of a doctor, a licensed psychologist and a social worker or a certified psychiatric nurse clinical specialist. Each of those people must be experienced in the evaluation of intellectually disabled persons. The report must find that the person is incapable of making informed decisions with respect to the conduct of his personal and financial affairs.

Under M.G.L. c. 201, Section 7, the probate court must hold a hearing on a petition for guardianship and must give at least seven days' notice of the hearing to the apparent heirs of the proposed ward and to the DDS.

NOTE: *Service Coordinators can provide you with assistance in complying with the steps needed to become a guardian. If you are interested in becoming a guardian to a person with an intellectual disability, it may be helpful to contact the person's service coordinator before you begin the process.*

Additional Resources

American Association on Intellectual and Developmental Disabilities

501 3rd Street, NW Suite 200
Washington, D.C. 20001
Telephone: (202) 387-1968 or (800) 424-3688
Fax: (202) 387-2193

www.aamr.org

Massachusetts Department of Developmental Services

Central Office

500 Harrison Avenue
Boston, MA 02118
(617) 727-5608
Fax: (617) 624-7577

www.mass.gov/dds/

Massachusetts Disabled Persons Protection Commission (DPPC)

300 Granite Street
Suite 404
Braintree, MA 02184
(617) 727-6465
Fax: (617) 727-6469

www.mass.gov/dppc/

VOR

836 S. Arlington Heights Rd. #351
Elk Grove Village, Illinois 60007
(877) 399-4VOR
Fax: 605-399-1631

www.vor.net

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Fax: (617) 624-7577
TTY: (617) 624-7783
Email: Info@state.ma.us

Regional Offices

Central West Region

171 State Avenue
Palmer, MA 01069
Teresa O'Hare, Regional Director
Terry.O'Hare@state.ma.us
(413) 284-1500
TTY: (413) 284-1554

Northeast Region

Hogan Regional Center
PO Box A
Hathorne, MA 01937
Amanda Chalmers, Regional Director
Mandy.Chalmers@state.ma.us
(978) 774-5000

Metro Region

200 Trapelo Road
Waltham, MA 02452
Gail Gillespie, Regional Director
Gail.Gillespie@state.ma.us
(781) 781-314-7501

Southeast Region

68 North Main Street
Carver, MA 02330
Richard O'Meara, Regional Director
Rick.O'Meara@state.ma.us
(508) 866-5000

To find DDS area offices, click on the DDS website at www.mass.gov/dds/