

THE MASSACHUSETTS COALITION
OF FAMILIES AND ADVOCATES, INC.
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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 persons with developmental 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 clients 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 have updated the Guide to reflect changes in DDS regulations, and have added new information on issues ranging from guardianship to getting SSI and Medicaid benefits.

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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 Others in the DDS system

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 others with intellectual and developmental 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 the person in your care has not yet been determined to be eligible, please link to Part 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 a person with a developmental disability, whether you happen to be a member of that person's family or his or her guardian. 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 an individual's ISP are not being met, there is a process for appeal.

NOTE: As we explain in both Part 4 of this Guide on the ISP process and in Part 5 on Guardianship, your advocacy rights on behalf of an adult with an intellectual or developmental disability are much more clear-cut if you are their guardian.

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

Be Pro-Active and Speak Out

As a family member or guardian of a developmentally disabled person, don't be afraid to speak directly to staff people or officials, or to telephone, email, or write letters on the person's behalf 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-based residence, contact the house director or supervisor and your service coordinator. Your service coordinator is your advocate in addition to coordinating the services a DDS client receives.

If your problem still isn't resolved, contact your 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.

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.

NOTE: In Massachusetts, community-based residential care is primarily provided in privatized group homes that are operated by nonprofit corporations. Those corporations are publicly funded via DDS.

A smaller network of community-based group homes consists of residences that are operated directly by DDS and that use state employees to provide direct-care services. We will refer to those residences in this Guide as Commonwealth-operated group homes, and the privatized residences as corporate provider-operated group homes.

The direct-care employees in Commonwealth-operated group homes tend to be better paid and better trained than their counterparts in corporate provider-operated group homes. As we discuss in Part 2 of the Guide on Getting Services, however, people waiting for residential care in the DDS system are usually not informed by DDS about the option of Commonwealth-operated group homes.

A third tier of residential care in Massachusetts is provided by Commonwealth-run developmental centers. Successive administrations have targeted four out of six of these centers, also known as Intermediate Care Facilities (ICFs), for closure since 2003. COFAR has fought to preserve these centers, which must meet strict federal standards for care and which serve persons with some of the most severe and profound levels of intellectual disability.

As of 2016, three ICFs remained open in Massachusetts: the Wrentham and Templeton Developmental Centers and the Hogan Regional Center in Danvers, MA.

We will discuss the option of Commonwealth-operated residential care facilities further in Section 2 of this Guide.

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 a DDS client 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.

The Use of Restraints, Seclusion, and Medication

COFAR has written and advocated on behalf of a number of persons in the DDS system who have been subjected to excessive and unnecessary restraints and seclusion and to inappropriate medications while in residential care settings.

DDS regulations establish standards over the use of these behavior modification techniques. Below are some of the key provisions of those regulations. If you believe a DDS client has been subjected to restraints, seclusion, or medication in violation of these regulations and/or the Standards to Promote Dignity regulations discussed above, contact your service coordinator. You can also contact us, and we will try to help.

The regulations governing restraints are complex. Below are some of the highlights of those regulations. (We suggest you consult the actual regulations if you have specific questions or concerns about the use of restraints or seclusion. The regulations can be found on the DDS website at www.mass.gov/dds :

Informed Consent: The regulations (115 CMR 5.08) require that a guardian or the individual (if not represented by a guardian) give their written consent prior to the use of certain behavioral modification techniques and medications. Consent is required prior to the admission to residential developmental centers as well.

Emergency Restraints

Emergency restraints - whether physical, mechanical, or chemical - may be used only in cases of emergency [115 CMR 5.11(4)]. Emergencies are defined in the regulations as the occurrence or "imminent threat" of serious self-injurious behavior or physical assault.

Physical restraint is defined as a "limitation of movement achieved by means of direct bodily contact between the individual and staff…" (115 CMR 2.01)

Mechanical restraint is defined as a "limitation of movement achieved by means of a physical device…"

Chemical restraint is defined as the "non-consensual use of medication, not for treatment, but for the purpose of impairing the individual's freedom of movement…"

The regulations (115 CMR 5.11) further state that:

- Emergency restraint may be used only after the failure of less restrictive alternatives or after a determination, based upon professional judgment, that such alternatives would be ineffective under the circumstances.

- An individual may be given chemical restraint only on the order of an authorized physician who has determined that such chemical restraint is the least restrictive, most appropriate alternative available.

- No medication may be used for chemical restraint purposes pursuant to a telephoned order unless the medication so ordered has been previously authorized as part of the individual's current treatment plan.

- Providers utilizing mechanical or physical restraint shall train all direct contact staff in the safe and appropriate use of such restraint.

- Any device used for mechanical restraint must provide appropriate and safe ventilation, and must allow for appropriate attention to the physical and emotional comfort of the individual in restraint.

- A written order from the head of the provider agency or from a physician must be issued prior to the use of mechanical or physical restraints.

- No individual shall be restrained for a continuous period exceeding six hours. No adult may be maintained in mechanical restraint for more than eight hours in any 24-hour period.

- Any minor placed in mechanical restraint or physical restraint shall be examined within fifteen minutes of the initial order for such restraint by an authorized physician, or, if an authorized physician is not available, by a registered nurse, nurse practitioner, or certified physician's assistant, provided, however, that said minor shall be examined by a physician within one hour of the initial order for restraint.

Seclusion and Other Behavior Modification Regulations

Requirements governing the use of seclusion fall under the Behavior Modification section of the regulations (115 CMR 5.14). Seclusion includes Time Outs, which are defined as:

> Socially isolating an individual by removing the individual to a room or an area physically separate from, or by limiting the individual's participation in, ongoing activities and potential sources of reinforcement, as a suppressive consequence of an inappropriate behavior.

Behavioral Modifications are classified as Level I, Level II, and Level III Interventions. Level III Interventions are defined as:

> Any Intervention which involves the contingent application of physical contact aversive stimuli such as spanking, slapping, hitting or contingent skin shock.

Level III Interventions also include Time Outs in which an individual is placed in a room alone for a period of time exceeding 15 minutes.

Level III Interventions must be certified by DDS and are subject to a number of other regulatory oversight standards under 115 CMR 5.14.

Citing the Regulations

If you have made a determination that there has been a violation of the regulations in the care of a developmentally disabled person, 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 a DDS client's Individual Support Plan.

Part 2: Getting Services (Determining Your Eligibility)

This second Section of this Advocacy Guide is intended for family members or guardians of developmentally disabled persons who are not currently receiving residential care or services from the Department of Developmental Services.

Note: In 2014, a new law was enacted (Chapter 226 of the Acts of 2014) that extends eligibility for services to people with Autism Spectrum Disorder and two other specified disabilities known as Prader-Willi Syndrome and Smith-Magenis Syndrome.

Until the enactment of this law, DDS had restricted eligibility for DDS services to people with "intellectual disabilities," as measured by a score of approximately 70 or below on an IQ test.

That left out many people with developmental disabilities, including autism, even though those conditions may severely restrict an individual's ability to function successfully in society. If those people score higher than 70 on an IQ test, they are routinely denied services.

However, in specifying three developmental disabilities that make individuals eligible for DDS services, the new law necessarily leaves out other conditions that often result in many of the same types of functional limitations, such as Williams Syndrome, spina bifida, and cerebral palsy. The new law was the product of closed-door negotiations among legislators, administration officials, and selected advocacy organizations.

Determining Your Eligibility for Supports and Services:

If you are a family member or guardian of a developmentally disabled person who 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 the individual's eligibility for those services.

In order to be determined eligible, a person must fit the DDS's definition of intellectual disability under the regulations; or that person may qualify for services if they have one of the three conditions noted above – Autism Spectrum Disorder, Prader-Willi Syndrome or Smith-Magenis Syndrome.

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**. Intellectual Disability originates before age 18."

Significantly sub-average intellectual functioning is defined as an intelligence test score that is indicated by a score of "approximately" 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 an individual 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

An indivdiual 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 corporate provider-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 helps 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."

Categories of Eligibility

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 developmental centers, also referred to as 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 living 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 and "severe functional impairments." (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 and to privatize residential and other services. ICFs/DD that have been closed since 2008 include the Fernald and Monson Developmental Centers and the Glavin Regional Center.

As of 2016, the Wrentham and Templeton Developmental Centers and Hogan Regional Center remained open, but the Templeton Center was expected to be converted from an ICF-level facility to Commonwealth-operated group homes.

Since most of the residents of the ICFs/DD are Ricci class members, they take priority for supports and services over other persons waiting for those supports in the DDS system.

Since 2008, most of the residents of the ICFs/DD that have been closed have been transferred by request to either the Wrentham Developmental Center or to DDS state-operated group homes.

For non-Ricci class members waiting for residential services, state-operated ICFs/DD and group homes have not been offered as a choice. Families and individuals appear to be directed almost exclusively to group homes run by corporate providers to DDS.

COFAR maintains that the state's failure to offer families and individuals the alternative of state-operated care is a violation of federal Medicaid Law, which requires that intellectually disabled individuals and their guardians be informed of the available "feasible alternatives" for care. In addition, the situation appears to violate the federal Rehabilitation Act, which states that no disabled person may be excluded or denied benefits from any program receiving federal funding.

In addition to provider-run group homes, DDS maintains a network of group homes that are staffed by departmental employees. State workers have better training on average than do workers in privately run residences, and have lower turnover and higher pay and benefits.

If you are a family member or guardian of an individual who has been found to be eligible for residential care by DDS, you have a right to ask for a placement in a Commonwealth-operated group home or in the Wrentham, Hogan or Templeton developmental centers. If DDS refuses to offer any of these settings as an option to you, let us know and we will try to help. In some cases, individuals have had to file suit to obtain placements in Commonwealth-run facilities.

Federal law states 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.

Waiting for Residential Placements

As noted above, while DDS does not acknowledge a waiting list, many people are waiting for residential placements in Massachusetts.

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 limitations, cognitive impairment, 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**.)

Social Security, Medicare, and Medicaid Benefits

The federal Social Security Administration (SSA) has two separate monetary benefits programs for which people with disabilities may qualify. Those programs are Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).

SSI and SSDI provide monetary benefits for people who qualify on the basis of disability, and, in the case of SSI, on the basis of financial need. Under SSDI, an intellectually disabled individual can qualify for benefits based on his or her parents’ work history if the parents are receiving Social Security benefits themselves.

You should apply directly to a local SSA office in order to apply for SSI and SSDI benefits, or you can apply online at www.socialsecurity.gov. Phone numbers and addresses for local SSA offices can be found at http://www.disability-benefits-help.org/social-security-disability-locations/massachusetts.

Monetary benefits available under SSI and SSDI can be used to obtain services in addition to the services provided directly through the Department of Developmental Services.

In addition, acceptance of an application for SSI and SSDI will automatically qualify an individual to receive Medicaid services in Massachusetts via the MassHealth program. Those MassHealth services include medical care, day habilitation, and adult foster care services. Other Medicaid services include speech, occupational and physical therapy and behavioral health services. Medicaid adds to any existing coverage such as private insurance.

Given that the approval process for SSI and SSDI benefits can take four to six months to complete, it may be advisable for you to apply separately to MassHealth for additional benefits that may be available under that program. You can apply for MassHealth benefits via the Massachusetts Health Connector website at https://www.mahealthconnector.org/, or you can call MassHealth at 1-888-665-9993.

Representative Payee

Should you apply for SSI or SSDI benefits for an individual with a developmental disability, you will probably also need to apply to the SSA to become the individual's "representative payee." As is discussed in Part 5 of this Advocacy Guide on **Guardianship**, a representative payee is an individual or organization appointed by SSA to receive SSDI and/or SSI benefits for someone who cannot manage their monthly benefits. The main responsibilities of a representative payee are to use the benefits to pay for the current and foreseeable needs of the beneficiary and to properly save any benefits that are not currently needed.

Special Education Services

If a developmentally disabled person 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 the individual'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 a developmentally disabled person 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.** 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 a developmentally disabled person 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 three of the other remaining ICFs/DD.***

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.

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.

   Starting in Year 2001, 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 fought to keep their children in the Center.

   Happily, in 2013, a federal judge formally ended the case, and the Patrick administration ended its efforts to evict the Seven Hills residents.

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.

   As noted in Part 2 of this Guide on **Getting Services**, DDS still appears to be unable to provide requested supports and services in a timely manner to many people who request them. DDS no longer admits, however, to maintaining a waiting list for services.

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 *l*ocation, 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 DDS clients from one location to another. The appeals effectively delayed the closure of the Fernald Center until late 2014.

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 clients 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 an individual has not yet been determined to be eligible, please link to Section 2 on **Getting Services (Determining Your Elligibility).**

This section is also intended to supplement Section 1 on **Advocating Effectively.** 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 a DDS client'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 (115 CMR 6.20: Introduction to Individual Support Planning) describe the ISP process as an ongoing one of "**establishing goals for individuals that are related to the individual's vision statement" and that are consistent with the following outcomes:**

1. Respect for the dignity and rights of each individual;
2. Humane and adequate care and treatment;
3. Self-determination and freedom of choice to the person's fullest capacity;

4. The opportunity to live and receive services in the least restrictive and most typical setting possible;
5. The opportunity to undergo typical developmental experiences, even though such experiences may entail an element of risk; provided, however, that the person's safety and well-being will not be unreasonably jeopardized; and
6. The opportunity to engage in activities and styles of living which encourage and maintain the integration of the individual in the community through individualized social and physical environments.

(These outcomes are similar to the Standards to Promote Dignity in 115 CMR 5.03, which are discussed in Section 1 of this Guide on **Advocating Effectively**.)

The **"Vision Statement,"** referred to above in 115 CMR 6.20, is described in the regulations (115 CMR. 2.01) as

> …a statement of what is important to the individual in his or her life. It describes the individual's preferences on how he or she wishes to live, work, and spend his or her leisure time and it identifies interests, relationships, and activities he or she would like to continue or explore.

The regulations note that this vision statement is not binding on DDS and cannot be appealed under the ISP appeals process (which is discussed below).

Family and Guardian Involvement:

The regulations (115 CMR 6.20) 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 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 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: As we discuss in Part 5 of this Guide on Guardianship, your rights as a family member to participate in the ISP process are more clear-cut if you are also the guardian of an individual in the DDS system. For example, the regulations [115 CMR 6.21(1)] state the following about who is involved in the development of the ISP:

The ISP must be developed with the fullest possible participation of each of the following persons, collectively referred to as the "team":

(a) the individual;

(b) members of the individual's family, **if authorized**;

(c) the individual's guardian(s), if any;

(d) the individual's service coordinator;

(e) representatives of providers of supports to the individual, provided that, at the individual's, guardian's, or family's request, the service coordinator may limit the participation of a provider representative to those portions of the ISP meeting which concern the supports being provided by the provider;

(f) the individual's designated representative and others who provide friendship and support to the individual or whom any of the participants consider necessary, unless the individual or guardian knowingly objects to such persons' participation.

NOTE 1: The "if authorized" language above regarding the involvement of the family in the development of the ISP is not further specified in the regulations. The regulations do not state who would authorize the family's involvement. In 2012, COFAR sent comments to DDS, objecting to "the addition of language (in the regulations) giving guardians and individuals the authority to exclude family members from participating in the ISP planning and process [115 CMR 6.21 (1 b) and 6.21(4)]."

NOTE 2: ***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 an individual to receive. Include your own goals for that person, 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.***

ISP Assessments and Consultations

In developing the ISP, DDS must conduct "assessments and consultations" in order to establish agreed-upon goals for an individual 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 an individual'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 a DDS client'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 sets forth the individual's Vision Statement, goals, and supports needed to reach those goals. The plan must describe the availability of those supports and must include strategies for meeting those needs of the person for which supports may not be available.

Outcomes

The regulations [115 CMR 6.23 (2)] provide more information about outcomes, which, the services in the ISP must promote. Those outcomes, as previously noted, 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).**

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 the Vision Statement and goals
- Discussion of recent experiences and events that may affect the person's immediate future, general health, safety, or long-term goals
- Discussion of the individual's current circumstances and supports
- Development of a "support agreement."

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

- Objectives and goals referred to in Checklist 1 above
- Strategies and supports to reach these goals **[ask that services on your wish list be included in the ISP support agreement]**
- The expected settings and 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 an individual 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 45 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 (**if authorized**), guardian, designated representative and providers [115 CMR 6.23(5)].

Within 10 days of receipt of the ISP, the service coordinator must notify the individual, his or her family, **if authorized**, and guardian(s), if any, of their right to a meeting with the service coordinator to explain the ISP.

If the area or facility director or his or her designee disapproves the ISP, in whole or in part, he or she must discuss this with the service coordinator and suggest changes to the ISP.

If the suggested changes would be considered modifications of the ISP (as we discuss below), the service coordinator must consult with the individual and other “team members” regarding the proposed changes to the ISP. The service coordinator *may* then reconvene the ISP meeting for the purpose of revising the ISP in accordance with the recommendations

of the area or facility director at the request of the individual or his or her family or guardian.

Under 115 CMR 6.23 (5)(c), the individual, 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].

NOTE 1: See our discussion below about family involvement in the ISP appeals process.

NOTE 2: ***As a guardian or family member, 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.***

Annual Review of ISPs

DDS's ISP regulations [115 CMR 6.24] require the ISP to be reviewed and updated on an annual basis. **The individual 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 the individual, and must review monitoring reports generated by the DDS and the provider. In consultation with the individual 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.

ISP Modifications

DDS regulations (115 CMR 6.25) spell out requirements and timetables for making changes at any time in an individual'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 DDS client or family member, **if authorized**, 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 both a right and a procedure with which to appeal the following categories of DDS decisions:

- The Department's decisions regarding the individual's eligibility for services

[See Part 2 in the Advocacy Guide on **Getting Services (Determining Your Eligibility)** for a discussion of eligibility regulations.]

- Goals and outcomes identified in the ISP
- Supports identified in the ISP
- Behavior modification procedures, medication, and restraints [These must be consistent with the Standards to Promote

Dignity described in Part 1 of this Guide on **Advocating Effectively**]

- The recommendation of the ISP team with regard to the individual's ability to make personal and financial decisions
- The development, review, and modification of the ISP; and
- Whether the ISP is being implemented.

NOTE: ***Appeals of DDS decisions to transfer an individual 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.

Who Can Appeal?

The language in 115 CMR 6.32 regarding who can file appeals of either eligibility decisions or the ISP is convoluted. We take the language to mean that appeals can be filed by either a family member, guardian, attorney, or designated representative. However, if the individual has a guardian, and that guardian is not a family member, only the guardian can file an appeal. In that case, no family member has the authority to file an appeal.

As is the case with the development of the ISP, as discussed above, we think this section of the regulations has, in some cases, inappropriately restricted the rights of family members. We will discuss this concern more in Part 5 of this Guide, on **Guardianship**.

The Informal Conference

The Informal Conference represents an attempt to reach agreement on the disputed issues involving either eligibility for services or the ISP, before the more time-consuming stage of the Fair Hearing (see below). Under 115 CMR 6.33 (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** to hold 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 DDS determines that appointment of an advocate would be in a client's or family member's best interest, the hearing officer or 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 a DDS client, 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 the client or family member.
- Following the Fair Hearing, the hearing officer must prepare and submit to the DDS commissioner a recommended decision which must 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."

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.
- Unless the parties agree otherwise, those portions of the ISP which are the subject of appeal shall not be implemented until after the informal conference described above, unless earlier implementation is necessary to respond to a serious or immediate threat to the health or safety of the individual or others.
- 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 an individual 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 this regulation.**

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 state 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 a developmentally disabled individual has not yet been determined to be eligible, please see Part 2 on **Getting Services (Determining Your Eligibility).**

This section is also intended to supplement Part 1 on **Advocating Effectively.** It should also be read in conjunction with Part 3 on **Protections for Ricci Class Members and non-Class Members** and Part 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 a developmentally disabled individual as a person incapable of caring for or managing their personal and financial affairs.

A guardian makes personal and medical care decisions for an adult individual with a developmental disability. A guardian should consider if possible the adult's expressed desires and personal values in decision-making, and should act in the person's best interest. Individuals with developmental disabilities, like everyone else, should be encouraged to participate in decision-making whenever possible.

A family member is often the best possible guardian for an incapacitated person because family members are likely to know that person well; they know his or her likes and dislikes, and are more likely to act in the person's best interest than is someone who does not see the person regularly or who is not familiar with the individual's life or the issues that are important to his or her wellbeing.

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.

A guardian can make decisions, both large and small, that affect an individual on a daily basis: Does the person have food that they like? Does he or she regularly get to their doctor's appointments? Does he or she regularly get out to activities they enjoy? Is the person's residence and day program appropriate for them? All of these decisions can be made better by having a caring guardian.

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 <u>not</u> competent to manage his or her affairs, the Department can seek to appoint a permanent or temporary guardian of the person. That appointed guardian might not necessarily be a person chosen by or even known to the individual or the individual's family, i.e. not necessarily a parent or sibling or other close relative.

- Even if you are a close relative of a person over 18 with intellectual disabilities, you will lose most if not 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 persons with developmental 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.

As discussed in Part 4 of this Guide on **Individual Support Plans (ISP's)**, guardians have much more clear-cut rights regarding participating in, and appealing, ISPs and DDS eligibility decisions than do family members who are not guardians. We discuss the issue of the appointment of corporate guardians and attorneys as guardians below.

Types of Guardianship

DDS regulations (115 CMR 5.07) specify the circumstances under which guardians can be appointed for persons with intellectual or developmental disabilities. The regulations recognize two broad types of guardianship services for persons with those 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 to 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.”** A representative payee of a person with a developmental disability has control over such things as the person’s Social Security benefits and any personal funds accounts that 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 an individual’s financial assets, such as bank accounts, paychecks or stocks and bonds. A conservator is also responsible for paying the person’s bills and debts out of the person’s assets; and a conservator is responsible for initiating or answering any legal actions that concern the debts owed by or to the individual.

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 a 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 provides 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 or provider agency, which may or may not have the resources to ensure adequate and competent care for your family member.***

COFAR has become aware of a number of cases in which family members have either lost their guardianship rights or failed to secure those rights. In a number of those cases, the families' wishes in the care of their loved ones have been overruled or even ignored by attorneys or other non-family guardians.

Litigation in probate court over guardianship rights can be extremely expensive and frustrating for families.

Effective guardianship involves responsibility and time, so you may want to consider a co-guardianship as well as naming a potential

guardian in your will. If you, as a guardian or potential guardian, do decide on a co-guardianship, your co-guardian should be either a member of your family or someone you trust as a friend of the individual and with whom you are in mutual agreement regarding the care of the person.

On no account, should decisions regarding guardianship or co-guardianship be left to DDS, for reasons discussed above.

Becoming a Guardian

The process of becoming a guardian is governed by statute in Massachusetts Uniform Probate Code.

The Probate Code as embodied in state law allows anyone to petition the probate court to serve as the guardian of an incapacitated person. Priority is given to the parent or spouse of that person, but probate judges have the discretion to ignore that priority and appoint anyone they believe is suitable. (M.G.L. c. 190B, s. 5-305).

NOTE: COFAR has long supported bills filed with the Massachusetts Legislature that would establish a presumption in probate court that the parents of a developmentally disabled person, or someone they designate, are the proper persons for appointment as guardians of that person.

In particular, a bill filed in the Massachusetts Legislature in January 2015 (H. 1459) would shift the burden of proof in favor of parents seeking guardianship.

As noted above, while the current law gives "priority" to the parent or spouse of an incapacitated person to be considered as a guardian, many parents and other family members are nevertheless often passed over by probate court judges in guardianship appointments.

Under current law, 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 Clinical Team Report dated within the previous 180 days.

The clinical team that writes the report must consist of a physician, a licensed psychologist and a social worker, each of whom is experienced in the evaluation persons with an intellectual disability. [M.G.L. c. 190B, s. 5-303]

Legal Representation and Reporting

The probate court is required to appoint legal counsel in a proceeding for the appointment of a guardian, conservator or in other matters relating to the incapacitated person if that person or someone on their behalf requests legal representation. [M.G.L. c. 190B, s. 5-106 (a)].

Legal counsel is automatically appointed in “Rogers guardianship” hearings in which the court is asked to authorize extraordinary treatment or care, such as administering antipsychotic medications and electro-convulsive therapy.

In petitioning for a Rogers guardianship, the person seeking guardianship must file a Clinician’s Affidavit in addition to the Clinical Team Report described above. The Clinician’s Affidavit must be completed by a licensed physician, psychiatrist, or certified psychiatric nurse clinical specialist who treats or has evaluated the incapacitated person (M.G.L. c. 190B, s. 5-306A).

At the time of the hearing on the Rogers guardianship petition, the petitioner would need to submit proposed Findings of Fact, and a proposed Treatment Plan.

Reporting to the Probate Court

Once you do become the guardian of an incapacitated person, you must report in writing to the court on the condition of the person and account for funds and other assets subject to your possession or control within 60 days following appointment. You must report at least annually after that, and when otherwise ordered by the court. (M.G.L. c. 190B, s. 5-309).

NOTE 1: The annual care plan referred to above should not be viewed as a means of advocating to the probate court for more or better services for the person you are representing as guardian. As noted in this Guide, you must direct your advocacy for more or better services to the individual’s service provider, DDS, your state representative, attorneys or others who deal with those issues.

In our experience, probate court judges do not ordinarily side with guardians or family members who bring up disputes they may be having with DDS over the quality or level of services that individuals in their care are receiving. In fact, probate judges tend, in our experience, to side with DDS in those cases.

As a result, if a guardian states in an annual care plan that he or she has been unable to obtain needed services for an individual from DDS, it may

suggest to the probate judge that the guardian is not effective, and it may have negative repercussions in future rulings from the court.

This does not mean that you should be untruthful in the care plan about the services the individual needs. You should list those services and state that you have been attempting to obtain them from DDS. We would recommend, though, that you not imply in the care plan that you are in a dispute with DDS over getting the services or that the probate court should assist you in that.

NOTE 2: ***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 or developmental disability, it may be helpful to contact the person's service coordinator before you begin the process.***

Resources

COFAR
http://cofar.org

VOR

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

http://vor.net

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

https://www.aaidd.org/

Massachusetts Department of Developmental Services

Central Office

Broad Street
Boston, MA 02119
(617) 727-5608

http://mass.gov/dds

Massachusetts Commission for the Protection of Persons with Disabilities (CPPD)

300 Granite Street
Suite 404
Braintree, MA 02184
(617) 727-6465
Complaint Hotline: 1-800-426-9009

https://cppdmass.gov/

DDS Offices

Central Office

Boston, MA

Sarah Peterson, Commissioner

Phone: (617) 727-5608

Email **sarah.peterson@mass.gov**

Meghan Allen, Ombudsperson: **meghan.l.allen@mass.gov**

Joseph Weru, Director of Human Rights: **Joseph.w.weru@mass.gov**

Jaclyn Grant, Statewide Director of Self-Direction:**jaclyn.grant@mass.gov**

Karl Farmer, Director of Investigations: **karl.farmer@mass.gov**

Katherine Alford, General Counsel: **katherine.b.alford@mass.gov**

Gabriella K. Eisner, Records Access Officer: **gabriella.k.eisner@mass.gov**

Regional Offices

Central West Region

Anthony Keane, Regional Director
Springfield, MA 01105

Phone: (413) 205-0800

Email: anthony.m.keane@mass.gov

Northeast Region

Bonnie Hungler, Regional Director

Hogan Regional Center
Hathorne, MA 01937

Phone: (978) 774-5000

Email: **bonnie.j.hungler@mass.gov**

Metro Region

Kaitlyn Spencer, Regional Director

Waltham, MA 02452

Phone: (781) 314-7500

Email: **kaitlyn.spencer@mass.gov**

Southeast Region

Richard O'Meara, Regional Director

Phone; (508) 866-5000

Email: **rick.omeara@Mass.gov**

To find DDS area offices, click on the DDS website at:
https://www.mass.gov/orgs/department-of-developmental-services/locations?_page=1