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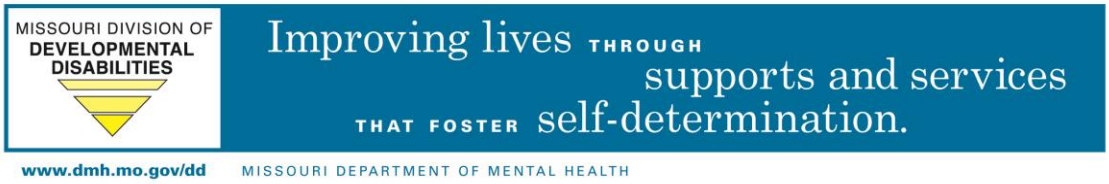

The Division of Developmental Disabilities posted draft rule amendments and two rule rescissions on the division's website during August and September of 2015, inviting public review and comment. This is a summary of comments received and responses regarding the following amendments and rescissions:

Proposed rescission: 9 CSR 45-3.020 Individualized Supported Living Services Definitions

- No comments were received in response to the draft proposed rescission.

Proposed rescission: 9 CSR 45-5.040 Missouri Alliance for Individuals with Developmental Disabilities

- No comments were received in response to the draft proposed rescission.

Proposed amendment: 9 CSR 45-3.030 Individualized Supported Living - Individual Rights (Title to be changed to Individual Rights)

The Consumer Advisory Leadership Team, an advisory group to the UMKC Institute for Human Development, made several recommendations during a discussion that took place on September 11. Recommendations are summarized as follows:

- Add "emotional abuse and financial exploitation" to the statement "To be free from physical and verbal abuse";
- Add "and provided in accessible formats" to the statement regarding access to and explanation of rules, policies and procedures;
- Add "and privacy of communication" to the right to use the telephone, internet or other forms of contact to communicate, and delete "with people."
- Add "To have freedom of choice of providers" to the list of rights;
- Add "To participate fully in the community" to the list of rights;
- Add "in accessible format" to the statement regarding explanation of rights, services, supports and clinical records;
- Delete "as required by the federal Health Insurance Portability and Accountability Act of 1996" from the statement regarding having clinical records maintained in a confidential manner, as it is not necessary to repeat the federal requirement in this rule, and

- Add “without retaliation or fear of retaliation” to the right to report violation of one’s rights.

  Response: These changes will be made in the draft amendment.

The Missouri Association of County Developmental Disability Services (MACDDS) submitted these comments and recommendations:

- If the division defines “individual” to include only a person who is found eligible, should the term “individual” rather than “person” be used in the purpose statement?

  Response: The amendment will be revised to use the term “individual” consistently throughout.

- RSMo 630.110 provides for limitations of rights of individuals living in residential facilities and participating in day programs.

  Response: The statement “unless otherwise stated by law” will be moved from (1) (B) to (1).

- MACDDS expressed concerns about granting broad rights without limitations, commenting on the need to sometimes limit rights to be consistent with an individual’s care, treatment, or habilitation, or for the safety of the individual or public. Concerns are expressed that a statement of unabridged rights will lead to conflicts when public administrators or guardians wish to restrict rights for the safety and protection of their wards. This concern was also expressed by reviewers submitting individual comments.

  Response: A statement will be added to the draft amendment that individuals are entitled to due process when rights will be restricted.

- MACDDS questions the necessity of this regulation, given that DMH has an established list of rights for individuals receiving services from the department.

  Response: Self-advocates, family members, and advocates generally agree that a clear statement of individual rights in regulation is a positive step, conveys respect for individuals served by the division and commitment to protecting individual rights. 9 CSR 45-3.030, promulgated over 20 years ago, addresses the rights only of a subset of individuals served by the division; those with the service Individualized Supported Living. The division would like to broaden this rule so that is clear all individuals served by the division have rights.

- A reviewer suggested the proposed amendment implies that people have an absolute right to all services, and that the division or providers will be required to provide telephones, internet access, and transportation to worship services.

Response: The proposed amendment is meant to be a statement of rights of individuals and does not create an entitlement to any particular service or level of service, nor does the proposed amendment alter eligibility for services and methods for service approval as set forth in the HCBS waivers and in 9 CSR 45 Chapter 2. The proposed amendment also does not alter the requirement that publically funded services not supplant natural supports, nor require that the division or a provider pay for goods and services not covered under the HCBS waivers.

- A reviewer asked whether the Title of Chapter 3 could be changed, as the proposed new title "Services and Supports" does not seem to flow with the purpose of the rule.

Response: To be consistent with the Secretary of State's rule making manual, all rules within a given chapter fall under the same chapter title. The current chapter title where Individualized Supported Living - Rights of Individuals rule is located is "Care and Habilitation." As this rule is meant to be a statement of the rights of all individuals served by the division, Chapter 3 seems the most appropriate location for a rule stating Individual Rights and the proposes to change the chapter title to more current terminology.

- A recommendation was made to add a statement that adults without guardians have the right to designate a representative.

Response: This will be added to the draft amendment.

- A recommendation was made to change "individuals eligible for services from the division" to "individuals receiving services from the division."

Response: This change is made.

- A reviewer recommended the addition of the statement "consistent with Positive Behavior Support principles and as outlined in the Individualized Support Plan" be added to (4) (A) regarding requirements for provider staff when dealing with disruptive, destructive, and inappropriate behavior. However, as this section of the rule is proposed to be deleted this change is not made.

A revised draft amendment to 9 CSR 45-3.030, incorporating recommendations from all reviewers will be posted for public review and comment on the division's webpage.

Proposed amendment: 9 CSR 45-3.040 – Rights of Protectors, Parents and Guardians (Title to be changed to Rights of Designated Representatives, Parents and Guardians.

The Missouri Association of County Developmental Disability Services submitted these recommendations:

- A designated representative is defined as a person selected by an adult who does not have a guardian to participating in the planning process. The regulation requires written consent of the individual for the designated representative to advocate on the person's behalf, but the consent may be revoked verbally or in writing. These provisions do not seem to be consistent with the HIPAA Privacy Rule or the Department's DOR 8.050. It is suggested that the appropriate process for written consent be the Authorization for Disclosure form, since PHI is involved.

Response: The Division agrees, however, the requirement to use a specific form would require inclusion of the form itself in the rule. Once a form or process is promulgated in rule, it may only be changed by formal amendment which may take months or years. Language will be added to the proposed amendment requiring that written consent for a designated representative must include authorization to disclose PHI in a manner consistent with the HIPAA Privacy rule, and may only be revoked in writing.

- MACDDS comments that the definition of Individualized Service plan goes beyond what would be considered a definition. As the requirements of an ISP are not the subject of this proposed regulation, the definition should be limited to the first sentence.

Response: This change is made.

- A reviewer noted a phrase apparently missing from the purpose statement and recommends inserting language so that it the purpose reads "…individuals <u>receiving services from</u> the division…"

Response: This change is made.

Proposed amendment: 9 CSR 45-3.060 Autism Services (Title to be changed to Services for Individuals with Autism Spectrum Disorder)

- The Missouri Parent Autism Committee recommended adding the statement "No member shall serve more than two (2) consecutive three (3)-year terms" to (6) (C) of the draft amendment regarding terms of committee members.

  Response: This change is made to the draft proposed amendment.

- The Missouri Association of Rehabilitation Facilities had comments regarding the proposed change from specifying the five autism project regions by name/geography with language from the statute stating "shall divide the state into at least five regions." MARF recommends the rule continue to be used to specifically identify the five project regions and their geography served.

  Response: The Division would like to provide the Missouri Parent Autism Committee and other stakeholders the opportunity to review and comment on the proposed revisions. The recommended changes are revised slightly to use the word "individual" rather than "client" and to delete "center" from references to regions.

- MARF recommends adding "social skills training" to the list of services provided by autism projects.

  Response: This will be added to the draft proposed amendment.