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Kathy Cooper

From: Liz Healey <lhealey@pealcenter.org>
Sent: Tuesday, December 20, 2016 12:22 AM
To: IRRC
Subject: PEAL Center COMMENTS ON Reference Regulation No. 14-540 (IRRC #3160)
Attachments: Imagine Different COMMENTS ODP Regulation 14-540.docx; Proposed rules for children Reg 14-540 from Imagine Different Coalition.docx

The PEAL Center believes that all children deserve to grow up in a loving family and that growing up in congregate settings is harmful to children.

The PEAL Center agrees with the comments and draft language prepared by the Imagine Different Coalition.

Please find the Imagine Different Coalition comments and proposed draft language attached.

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COMMENTS ON PROPOSED REGULATION NO. 14-540
by the IMAGINE DIFFERENT COALITION

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We appreciate the opportunity to provide comments on behalf of the Imagine Different Coalition, a group of parents, advocates, and professionals from across the state that has come together because of a common concern about children with disabilities growing up in congregate care facilities instead of well-supported and loving families.

Developmental advantages of family life and concerns about congregate care for children have been confirmed by a recent article of the American Academy of Pediatrics¹ which identifies factors inherent in congregate care that render it potentially harmful to children.

We sincerely appreciate the extensive review and process for stakeholder input that went into the proposed changes. We also appreciate DHS's effort to expand protections for health, safety, and well-being and promote opportunities afforded by inclusion. Our Coalition's focus is on children and youth with developmental disabilities under the age of 21. Our comments are therefore directed at the implications of the proposed regulation changes for this group. While our interest is in children and youth under age 21, our comments recognize the need to make distinctions between minor children (under age 18) and young adults ages 18-20.

We are aware that there are children and youth living in facilities covered by the 6400 regulations. We understand there are approximately 400 children under 21 living in pediatric health care facilities, some of which are licensed under 6400 regulations. We also know of large residential facilities providing long-term care that are not funded under waivers that serve children under 21. We believe the proposed changes do not adequately address their needs while they are there, nor do they address the need to find more appropriate living arrangements for them.

Finally, to the extent that the proposed 6100 regulations cover 3800 licensed facilities, they would likely affect more than 2000 children with developmental disabilities, mostly ID and Autism, and would provide an opportunity to apply permanency planning principles which we propose to begin to effectuate more family-based services.

Below we first identify our concerns across the regulations and then identify concerns related to specific rules. At the end we close with proposed language for new rules for consideration.

We understand DHS will reconvene the stakeholder workgroup prior to finalizing the proposed changes. We suggest a subgroup be convened to focus on edits needed to address children's issues. The Imagine Different Coalition offers our assistance and would welcome the opportunity to contribute positively to edits that better serve and protect children and youth.

¹ Friedman SL, Norwood, KW, AAP COUNCIL ON CHILDREN WITH DISABILITIES. Out-of-Home Placement for Children and Adolescents with Disabilities—Addendum: Care Options for Children and Adolescents with Disabilities and Medical Complexity. *Pediatrics*. 2016;138(6):e20163216.

DRAFT COMMENTS ON PROPOSED REGULATION NO. 14-540

Overall across rules

1. **Intent regarding children.** We see the need for an articulation of intent, or regulatory preamble, regarding children covered under these regulations. We suggest the following:

The proposed regulations strive to ensure the basic needs for safety, security, and stability for children. A family is the most natural, healthy, efficient and effective way to meet those needs. The state and its service providers must work together to provide encouragement and support for well-functioning families and ensure that each child receives the benefits of being part of a successful permanent family as soon as possible.

2. **Other developmental disabilities.** We applaud the inclusion of autism but we recommend the inclusion of other developmental disabilities as well, at least with respect to children. The proposed rules have applicability to protections also needed by service recipients with developmental disabilities other than ID or autism. We understand eligibility for particular services is a separate issue, but children with Cerebral Palsy, Muscular Dystrophy, Spina Bifida, paralysis, and respiratory disease, among other conditions, sometimes live in large 6400 licensed facilities and have no other regulatory protections. In addition, children with other developmental disabilities, now living in large MA funded 3800 licensed facilities could thrive in 6500 licensed homes. These children should not be excluded from the benefits and protections of these regulations. Furthermore, future changes might expand eligibility to services covered by the regulations (e.g., proposed waiver amendments). We believe now is the time to add protections for other developmental disabilities to prevent the need for rewriting in the future.
3. **Insufficient protection for children.** As written, the rules are oriented to adults. No specific mention is made of children or special considerations warranted by childhood. We would like to see specific attention to the following children's issues:

- a. **Permanency planning.** The purpose of the rules is identified as "facilitating the person's ongoing growth and development." Permanency is a developmental need for children that should be reflected in the rules. Family living is the preferred permanency goal for minor children. A permanency goal for a young adult should consider his/her preference for family life, or should consider a small community home that meets the HCBS requirements under chapter 6100.

Permanency planning was formerly a waiver service but was deleted on the premise that support coordinators should engage in permanency planning as part of their responsibilities. Adding requirements for permanency planning for children is needed in a number of areas including:

- i. Core competencies. Permanency planning should be one of the core competencies identified as part of “supporting individuals in maintaining relationships.”
- ii. Family relationships. Permanency should be addressed in the “Role of family and friends.”
- iii. Person-centered Support Plan (PSP). A comprehensive plan for any child should require addressing permanency.
- iv. Supports coordination. Permanency planning should be an identified responsibility of Support Coordinators and Targeted Support Management.
- v. Training. Permanency should be added as one of the required core courses.
- vi. Assessments. A permanency assessment should be a required assessment.

We suggest a **definition of permanency**: *a permanent living arrangement for children with the primary feature of an enduring and nurturing parental relationship facilitated by family support.*

We suggest permanency planning be mandated by regulation and require use of a Department Permanency Planning tool (which would be developed outside the regulatory process) to provide a uniform guide for permanency assessments and planning. The tool should require discussion of:

- i. Reasons for movement from the family home
 - ii. The permanency goal
 - iii. Potential for family living
 - 1. Return home
 - 2. Maintaining relationship with parents and siblings
 - 3. Living with relatives
 - 4. Living with others with existing close relationships
 - 5. Living with Lifesharing families or other family living arrangements
 - iv. A timetable to achieve the permanency goal
- b. Facility use by children.** Use of congregate care facilities for long-term living for children is inappropriate and potentially harmful for child development. Planning should require prevention if possible, the shortest use possible if necessary, and transition to family life as soon as feasible.
- i. There should be specific preference for family life over the use of non-family based residential facilities for long-term care for children.
 - ii. Use of facilities by children should be tracked to enable ODP to identify and address concerns.
 - iii. Existing facilities licensed under 6400 regulations that are not part of the waiver program would not be limited to a capacity of eight or fewer under the proposed rules. Consider limiting new admissions of children for long-term care into existing large facilities that are licensed under these regulations.

c. **Regulations appropriate for adults inappropriately applied to children.** A number of sections address rights and protections that are not appropriately applied to children, or at least not to young children. For example, the right to:

- Choose a willing and qualified provider
- Choose where, when, and how to receive needed support
- Unrestricted access mail unopened and unread by others
- Unrestricted and private access to telecommunications
- Lock the individual's bedroom door
- Manage and access the individual's own finances

We suggest inserting qualifying language regarding *age and developmentally appropriate rights*.

4. **Inadequate assurances for engagement and decision-making of parents or guardians of minor children.** A number of sections refer to "persons designated by the individual" who can be involved in planning and decision making. Involvement of families is to be facilitated "at the direction of the individual." In addition, references are made to court-appointed legal guardians. These references suggest optional engagement of parents of minor children or do not recognize their legal authority without court involvement. These references should be changed to require that every effort is made to ensure the involvement of and respect for the decision-making authority of a parent of a minor child. This would be consistent with the new federal HCBS rules.

5. **Preadmission determinations and planning.** The rules speak to the importance of strict conditions and procedures for discharge planning if an individual needs to transition to a new provider. However, the regulations do not similarly provide protections for the determination of appropriateness of admission and planning for the initial transition from a family home. Movement from a family home can be traumatic, particularly for children, and the appropriateness of admission to a residence should be addressed. We suggest insertion of language regarding determination of appropriateness of admission that takes into account exploration of permanency-based alternatives prior to admission.

6. **Education.** The 6400 and new 6100 regulations have no provisions related to the educational rights of children. This reflects the seeming unawareness that there are children residing in 6400 licensed facilities, including large facilities.

- a. Residential providers must be made aware of their obligations to ensure that school-age residents have access to school through the local public school district, and to educational decision-makers who are not employed by the provider agency as required by the IDEA.
- b. DHS policy, reflected in the 2010 Bulletin OMHSAS-10-02 and signed by the deputies for ODP, OCYF and OMHSAS, and consistent with PDE policy as well, recognizes the right of children in residential care to attend their local public

schools rather than segregated on-grounds schools unless prohibited by court order or specified in an IEP or 504 service agreement in accordance with applicable laws (e.g., the IDEA and 22 PA Code Chapter 15). The Bulletin therefore prohibits residential facilities from bundling residential services with educational services – i.e., requiring children to attend the facility’s school as a condition of receiving their residential services. This policy is consistent with the principles of HCBS and should be codified in ODP regulations.

- c. Infants and toddlers with disabilities are entitled to Early Intervention services which are critical to their healthy development. Residential providers must ensure that the appropriate referrals are made. While DHS has more detailed Bulletins on forms and procedures, the basic requirement of referral should be codified in these regulations as well. We are aware of infants and toddlers living in both 3800 and 6400 licensed facilities. These very young children should not be forgotten.

7. **Coordination with other state agencies.** The proposed rules state an intent to assure “compliance across multiple funding sources” and “across programs and funding sources.”

- a. **Coordination.** OVR is specifically named in the section on employment. All children are involved with education yet there is no mention of the Department of Education. A significant number of children involved with OCYF are living in residences covered by these rules, yet there is no mention of OCYF. Coordination with education and OCYF has particular implications for a number of areas including:
 - i. Supports coordination
 - ii. PSP participation and development
 - iii. Transition planning
- b. **Data sharing.** Residential facilities serving children with developmental disabilities funded by other state agencies should be required to report their admission and long-term stays to BHSL and ODP for tracking purposes in order to enable identification of barriers to family living and concerns involving interagency coordination.

6100

- 1. **Mirror changes suggested above.** Suggested language for additions to the 6100 regulations is offered at the end of our comments.
- 2. **Address medical needs beyond medication administration.** Sections 6100.461-470 devote two pages to medication administration but do not address other medical management and oversight needs with any significant detail. We are particularly concerned about protections through management and oversight of the needs of children with special health care needs including complex health care needs. We

understand a number of children are living in pediatric health care facilities licensed under 6400s regulations with Medicaid funds or county funding.

3. **Definition of family.** In Section 6100.2 a family is defined as “a natural person that the individual considers to be part of his core family unit.” Section 6100.186 requires the provider to involve the family “at the direction of the individual.” For a minor child, this inappropriately leaves identification and involvement of a family open to the child’s determination. We recognize families can take many forms through relationships involving blood, marriage, tribe, clan, or significant positive affiliations. We want to assure the feature covered in a definition of a family for a child focuses on a parental figure represented by the presence of at least one loving adult committed over the long term to nurture, guide, and assure a secure everyday home life through a child’s life. In addition, the definition should acknowledge relationships with siblings.
4. **Room and board agreements.** Section 6100.688 identifies rules related to room and board residency agreements. Directions are given for two situations which require a designated person to sign an agreement: (1) when an individual has a court appointed guardian and (2) when an individual is over the age of 18. The situation of a parent or guardian signing for a minor child is unaddressed.
5. **Supports coordination.** The responsibilities and preparation of supports coordinators serving children need to be supplemented.
 - a. **Training for supports coordinators.** Section 6100.803 currently includes: facilitation of person-centered planning, conflict resolution, human development over the lifespan, family dynamics, and cultural diversity. Permanency for children should be added as a training requirement. Content should include the benefits of family life and the developmental risks of facility living.
 - b. **Monitoring and reviews.** Given the developmental risks for children inherent in facility living, there should be a requirement to identify the frequency of face-to-face visits by the supports coordinator in the PSP for all children served in facilities. Section 6100.803 requires the support coordinator “to document if the individual continues to need the authorized level of residential habilitation every 6 months.” We suggest the requirement be expanded and increased in frequency to document a review of the permanency plan of the PSPs for children (suggested earlier) to assure timely progress toward transition back to family life, either by return to family or by moving to another family living arrangement.

[See end of document for suggestions for child-related regulations to include in the 6100 chapter.]

6400

1. **Mirror changes suggested for 6100s.**

6500

1. **Mirror changes suggested for 6100s.**
2. **Relationship with parents or guardians of minor children.** Section 6500.1 describes the Lifesharing program as “based on the importance of enduring and permanent relationships.” It is critical that there be clarity about the relationships (a) between a child and his/her parents and siblings and (b) between the child’s family and the Lifesharing family. This should be specifically required in a permanency plan as part of the PSP (suggested earlier).
3. **PSP participation and development.** Section 6500.152 identifies the team members to be involved in the development of the PSP. The team members do not include the parent, guardian, or OCYF caseworker for a dependent child unless designated by the individual, nor is the Lifesharing family included. Involvement of these participants should be required. While a “program specialist” is included, it is not clear that this is the Lifesharing specialist.
4. **Training.** Section 6500.47 and 48 identify requirements for orientation and annual training for the primary caregiver and the Lifesharing specialist, including training related to “supporting individuals in maintaining relationships.” This should include permanency planning for children.
5. **Designation of responsibility.** Various sections refer to “primary caregivers,” “lifesharers,” “household members who have direct contact with individuals,” and “direct service workers.” Section 6500.44 requires specification of “the staff qualification and staff ratio” in the PSP. Clarification should be provided as to who constitutes staff.
6. **Oversight protections.** Section 6500.43 identifies requirements for Lifesharing Specialists. There is no requirement identified for how frequently the Lifesharing specialist or supports coordinator should observe the individual in the Lifesharing family home. For a Lifesharing entity that is not under an agency, there is only a requirement for an annual inspection to assure compliance with the regulations. There needs to be more frequent oversight for children living in Lifesharing families. For children with significant health concerns, frequent oversight by a health care professional should be required.
7. **Transportation.** Since these settings are family homes, it is important to clearly identify requirements for suitable family transportation, especially accessible transportation to enable community inclusion on a routine basis.
8. **Preadmission determination of adequacy of Lifesharing home for specific individual/child.** Given that the living arrangement is a family home, it is particularly

important that consideration be given to the quality of the match between the child and the lifestyle as well as capabilities of the members of the Lifesharing family, both to assure that a child's needs can be met and to assure the longevity of the placement. Section 6500.151 allows for assessments 60 calendar days *after* admission except for initial assessments of adaptive behavior and level of skills which are required within 6 months prior to admission. This requirement does not offer sufficient considerations beyond the child's skills and behavior to enable assurance of an appropriate match or longevity.

SUGGESTED LANGUAGE FOR ADDITION TO CHAPTER 6100

PROPOSED RULES RELATING TO CHILDREN AND YOUTH

6100.900 This section applies to children under the age of 21 who have developmental disabilities as defined by the federal Developmental Disabilities Assistance and Bill of Rights Act, 42 USC 15002.102(8)

6100.901 Permanency shall be a goal in all PSPs for children. Permanency means a living arrangement for children with the primary feature of an enduring and nurturing parental relationship facilitated by family support. Family living is the preferred permanency goal for minor children, and either family living or a small community home that meets the HCBS requirements of chapter 6100, along with a strong connection to family (as defined at 6100.3) is the preferred permanency goal for older youth. Permanency goals should also include maintaining sibling relationships whenever possible.

6100.902 Children and youth with Developmental Disabilities may reside in congregate care facilities only when:

- a) A Support Coordinator and/or TSM has been assigned to the child or youth.
- b) The residential provider files a report identifying the child or youth with ODP and BHSL within ten days of placement, or of the effective date of these regulations, in a manner prescribed by ODP.
- c) The child is listed on the emergency waiting lists of any waivers for which he or she is eligible.
- d) The Support Coordinator or TSM ensures the development of a PSP that includes a permanency plan, consistent with the Department's Permanency Assessment and Planning Instrument. For children adjudicated dependent, any permanency plan developed by the child welfare agency shall be coordinated with the PSP.
- e) The Department's Permanency Assessment and Planning Instrument shall identify the permanency goal and plans to achieve it and include a detailed description of the barriers to permanency, the steps taken to address the barriers, and what, if any, funding or service availability change would allow for permanency.
- f) For long-term placements made after the effective date of these regulations, the capacity of the facility is four or fewer, unless a regulatory waiver pursuant to section 6100.43 has been granted.
- g) For placements made after the effective date of these regulations, the Support Coordinator, or TSM documents best efforts to achieve the permanency goals of the PSP before placement.
- h) The Support Coordinator or TSM documents compliance with the PSP, including

- documentation of visits to the child or youth at the frequency required by the PSP.
- i) The Permanency Assessment and Planning Instrument and the PSP are updated every three months until the permanency goal has been achieved.

6100.903 Parents or legal guardians of minor children are required members of the PSP Team. For youth 18-21 who are adjudicated dependent, the CYF agency representative is a required participant in the development of the PSP unless the youth objects. A form shall be provided to the youth to explain this right and to document an objection.

6100.904 Training in permanency planning principles shall be a requirement for all Support Coordinators, TSMs, case managers, and residential program specialists who serve children and youth.

6100.905 Support Coordinators, TSMs and residential facility providers shall ensure that all infants and toddlers they serve are referred to Early Intervention programs.

6100.906 Support Coordinators, TSMs and residential facility providers shall ensure that all primary and secondary school eligible children:

- a) are enrolled in the local school district in which they live or in another responsible school district;
- b) have an educational decision-maker consistent with the requirements of the IDEA, or a request for an educational decision-maker has been made to the responsible school district or court.

Residential providers may not make attendance at an on-grounds school, or a school operated by the residential provider, a condition of the residential placement, and must so inform the educational decision-makers for each child.

6100.907 Providers must ensure that the health and medical needs of participants are met. In the case of children and youth with long-term medical needs, whose residence is covered by these regulations:

- a. At least monthly oversight by a healthcare professional is required;
- b. A health-care plan, identifying all the child's medical needs, including but not limited to amount and frequency of nursing, home health aides, therapies, medications, behavioral supports, durable medical equipment and regularly scheduled physician visits, shall be signed by a physician, implemented, and kept in the residential provider's and Support Coordinator or TSM's file.
- c. For children and youth who have been adjudicated dependent, the health-care plan shall be shared with the county child welfare agency unless sharing such document is otherwise restricted by law.

6100.908 Department offices, including at least ODP, OCYF, OLTL and OMAP shall enter into memoranda of understanding (MOUs) to ensure that the resources of all systems are available to meet the permanency and transition needs of dependent children and youth. The MOUs should include resolution of conflicting licensing requirements, delegation of funding responsibilities between the agencies, sharing of information, and consideration of creative options that promote permanency.

6100.909 Children and youth with developmental disabilities who are adjudicated dependent and are receiving services covered by these regulations shall be assured the following:

- a) ODP shall assign a Support Coordinator or other case manager.

- b) The county child welfare agency and the ODP or delegated county agency shall, upon the child's sixteenth birthday or before placement in a congregate care facility, whichever occurs first, enter into an agreement consistent with the MOU to meet the permanency goals of the PSP as soon as possible and to ensure a smooth transition to adult services.
- c) If there is a dispute between the agencies about responsibility for payment for needed services a DHS designee will resolve the dispute in accordance with the MOU.

6100.910 Section 6100.223(11) shall not be applied to children. For older youth, the PSP must include services and supports that are needed to pursue competitive, integrated, employment in the present, or are needed to improve the ability to pursue such employment in the future.

SUGGESTED LANGUAGE FOR ADDITION CHAPTER 6100 PROPOSED REGULATION NO. 14-540
by the IMAGINE DIFFERENT COALITION

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- d) The Support Coordinator or TSM ensures the development of a PSP that includes a permanency plan, consistent with the Department's Permanency Assessment and Planning Instrument. For children adjudicated dependent, any permanency plan developed by the child welfare agency shall be coordinated with the PSP.
- e) The Department's Permanency Assessment and Planning Instrument shall identify the permanency goal and plans to achieve it and include a detailed description of the barriers to permanency, the steps taken to address the barriers, and what, if any, funding or service availability change would allow for permanency.
- f) For long-term placements made after the effective date of these regulations, the capacity of the facility is four or fewer, unless a regulatory waiver pursuant to section 6100.43 has been granted.
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