

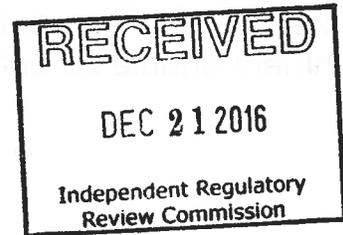
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#14-540-133

**Kroh, Karen**

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**From:** Mochon, Julie  
**Sent:** Tuesday, December 20, 2016 8:37 AM  
**To:** Kroh, Karen  
**Subject:** FW: Regulation No. 14-540 - Comments  
**Attachments:** DRP\_comments\_14-540.pdf



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**From:** Eric Howell [<mailto:ehowell@disabilityrightspa.org>]  
**Sent:** Monday, December 19, 2016 1:18 PM  
**To:** Mochon, Julie  
**Cc:** Thaler, Nancy  
**Subject:** Regulation No. 14-540 - Comments

Hello Ms. Mochon,

Attached, please find Disability Rights Pennsylvania's comments on Regulation No. 14-540.

Sincerely,

Eric Howell  
Executive Assistant  
Disability Rights Pennsylvania  
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Please Note: my email address has changed. [ehowell@disabilityrightspa.org](mailto:ehowell@disabilityrightspa.org)

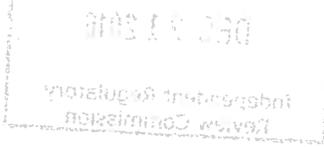
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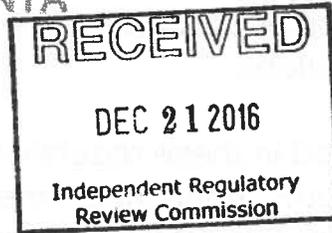
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# DISABILITY RIGHTS PENNSYLVANIA



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December 19, 2016

Julie Mochon, Human Services Program Specialist Supervisor  
Office of Developmental Programs  
Room 502, Health and Welfare Building  
625 Forster Street  
Harrisburg, PA 17120

Re: Regulation No. 14-540

Dear Ms. Mochon:

Disability Rights Pennsylvania (DRP) is the organization designated pursuant to federal law to protect the rights of and advocate for Pennsylvanians with disabilities. DRP's clients include children and adults with disabilities across Pennsylvania who receive or are in need of services administered by the Department of Human Services (DHS) so that they can live and work in the community.

DRP appreciates the opportunity to comment on the proposed 6100 regulations and accompanying changes to associated regulations. Our primary focus is on preserving the rights of people with disabilities and to advocate their health and safety. With that in mind, we make the following suggestions and comments for your consideration.

For far too long people receiving services to support their needs related to autism were left with few options to preserve rights and protect their health and safety. DRP was pleased to see the inclusion of services for people with autism in these regulations. However, we do have some concerns with the exclusions that were granted at the same time in the proposed regulations. We will discuss those later in this document.

## **Protecting and advancing the rights of people with disabilities**

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Inclusion of base-funded services in the proposed regulations is a welcomed addition. This will help ensure the health and safety of individuals in programs funded by base dollars as well as protect their rights. This is a much needed addition to the regulations.

A vital safety protection was included in these regulations when background checks were expanded to include household members, life-sharers, volunteers, etc. We applaud DHS for this step toward increased protections for vulnerable individuals.

We support the limit on new residential programs to include a maximum of 4 people, however, we are concerned that already existing larger residential programs are not only allowed to continue, but are allowed to relocate to a new site without complying with the proposed 6100 regulations concerning program size.

We support the limit placed on sheltered workshops/day programs, etc. and the move toward more community-integrated settings and real jobs at a competitive wage. Additionally, the proposed amendments to vocational programs to increase/expand individual rights is welcomed and a much-needed protection.

We applaud DHS for creating an expectation of positive interventions to address behavioral, medical and other concerns. This is long overdue. This further enhances health, safety and individual rights and eliminates the allowance of the use of restraint and seclusion to punish people.

Finally, for many years individuals, families and legal guardians have requested access to documents pertaining to incidents that are reported to ODP. We commend DHS in the creation of regulation that requires that the incident reports be made available to the individual and those they designate. This is a huge step forward in protecting the health, welfare and rights of individuals.

In addition to the positive changes in these proposed regulations we found a number of issues that cause us concern:

- 1. Streamlining and Promoting Consistency in ODP Regulations**

a. Unnecessary Repetition – One of the stated purposes of the proposed regulations is to streamline the regulations and to promote consistency among the various types of services and providers. Yet, there appears to be significant overlap and at times complete duplication of many of the new standards (*e.g.*, incidents; positive interventions; individual rights; person-centered planning; medications) in each of the chapters relating to various types of services. We would recommend that DHS eliminate the repetition and simply include all provisions that relate to all services in the proposed 6100 regulations (where most are also included).

b. Adult Autism Waiver Exemptions – Proposed Section 6100.801(b) exempts services under the Adult Autism Waiver from many of the proposed regulations, including those governing rates. This exemption contravenes the preamble's statement that the proposed regulations are intended to remedy the inconsistency between regulations governing individuals with intellectual disabilities and those with autism caused by regulatory exemptions for the Adult Autism Waiver. 45 Pa. Bull. 7061, 7061-62 (Nov. 5, 2016). DRP recommends that the Adult Autism Waiver be subject to the same regulations as ODP's other waivers.

## 2. Payment

a. Fee Schedule Rates – (1) Proposed Section 6100.571 indicates that DHS will use "market-based data" to establish fee schedule rates at least every three years. DRP first recommends that fee schedule rates be reassessed annually to assure that the rates are competitive so that qualified staff are available to provide services. (2) Subsection (c) identifies various factors that DHS will "review and consider." The language should require DHS to take the listed factors into account; not merely "consider" them. (3) While the factors listed in subsection (c) include "staff wages" and "staff-related expenses," this is not sufficient. The fee schedule rates should be sufficient to pay a living wage in the relevant geographic area, including benefits. (4) The proposed regulations should identify which services will be subject to fee schedule rates, as do the current regulations. 55 Pa. Code § 51.53(b)(2).

b. Eligible Rates – Based on DRP's discussions with ODP staff and attorneys, DRP understood that ODP intended to substantially overhaul its

system for establishing eligible rates for residential habilitation services. In particular, we understood that it was DHS's intent to move from a cost-based system to a system focused on the "acuity" or specific service needs of the individual participant. As such, DRP is both puzzled and disappointed that proposed Sections 6100.641-6100.646 indicate that DHS intends to continue using a cost-based model to set the eligible rates. Some specific concerns with DHS's regulations governing eligible rate payments include:

- Proposed Section 6100.642(a) states that eligible rates for existing residential habilitation programs will be based on cost reports, which means that the rates will neither reflect actual, current costs nor the actual needs of the residents.
- Proposed Sections 6100.642(b)-(c) indicate that DHS will use the area adjusted average rates for existing residential habilitation programs to set the eligible rates for new residential habilitation programs. Again, this will lead to rates that are divorced from both the actual costs and the actual needs of the residents in the new programs.
- Proposed Section 6100.642(d) states that DHS will assign the lowest rate calculated statewide for all providers in the event a provider fails to timely comply with the cost-reporting requirement. In effect, this penalizes the residents, leading to deterioration in the quality of services offered or even termination of the residents' services and loss of their homes.
- Proposed Sections 6100.645(f) and 6100.646(b) indicate, respectively, that DHS may still use "outlier analysis" and "rate assignment processes" to establish eligible rates. DHS's use of the outlier review has led to substantial reductions in eligible rates for residential providers who serve the individuals with the most intensive support needs and whose costs, therefore, are most likely to be "outliers." Assuming that the "rate assignment processes" referenced in proposed Section 6100.645(f) means the rate adjustment factor which DHS has used in the past to reduce eligible rates due to inadequate appropriations, that process too undermines the creation of quality residential supports. Both of these processes lead to payments that are inadequate to meet the

actual needs of residents, particularly those with complex or challenging needs and make providers particularly reluctant to serve such individuals.

In the preamble to the regulations, DHS states that “the current system of cost-based reimbursement for residential habilitation is costly and inefficient” and that there needs to be a transition from a “cost-based system to a more viable payment system.” The problem with the cost-based system is not that it is “costly and inefficient.” Rather, the problem is that it results in eligible rates that are inadequate to assure that participants with more intensive service needs (e.g., those with significant behavioral health or physical health issues) have prompt access to residential habilitation services. In addition, the cost-based system (including the use of the outlier review process and threats of application of a rate adjustment factor) creates uncertainty that compounds the reluctance of providers to serve those participants with more intensive service needs. DHS’s cost-based system violates Title XIX of the Social Security Act by denying participants services to which they are entitled and the integration mandates of the Americans with Disabilities Act and Rehabilitation Act by causing the institutionalization of such participants or placing them at serious risk of institutionalization.

c. Start-up Costs – Proposed Sections 6100.670-6100.672, addressing start-up costs, provide no assurance that DHS will authorize compensation for start-up costs that are sufficient to overcome the current impediments to the development of new residential habilitation programs.

- Section 6100.670(b) states that start-up costs “may” be authorized by DHS. Compensation for start-up costs is essential to program development. As such, DHS’s compensation for start-up costs must be mandatory rather than optional.

- The proposed regulations say nothing about the amount of start-up costs that will be available. The current \$5,000 cap, 55 Pa. Code § 51.111(f), has proved inadequate in many instances, particularly for providers serving clients with challenging and complex needs (e.g., where staff may require more intensive training before the program begins).

■ Proposed Section 6100.670(c) states that start-up costs “shall be authorized in accordance with Standard Operating Procedure 98-5 ....” SOP 98-5 excludes the costs of acquiring or constructing long-lived assets and getting them ready for their intended uses. Accordingly, DHS’s proposed regulation would not compensate providers for the cost of purchasing or building housing, which arguably is one of the largest actual costs of starting a new residential habilitation program. Moreover, the SOP arguably would also exclude the costs of accessibility modifications if it constitutes getting a long-lived asset ready for its intended use. The inability to compensate providers for the costs of acquiring property and funding accessibility modifications may well impede development of such residential habilitation programs, particularly for those with physical disabilities. DHS’s exclusion of compensation for costs not subject to SOP 98-5 is at odds with its current policy embodied in 55 Pa. Code § 51.111(g).

DRP urges DHS to modify this regulation to assure that residential habilitation providers are compensated adequately for their start-up costs, including the costs of long-lived assets and modifications to those assets. Like eligible-rates, the lack of access to sufficient start-up costs also has resulted in the inability of individuals with challenging needs (who often need new programs) to timely access residential habilitation services in violation of federal law.

d. Ineligible Rates – Proposed Section 6011.711 states that DHS will establish ineligible rates based on a “market-based approach” based on various factors and will review them at least once every three years. There needs to be specific assurance that the ineligible rates, together with contributions from the individuals and other benefits available for room and board, are sufficient to cover the costs of room and board, including the costs of wear and tear.

### 3. Abuse, Neglect and Exploitation

a. In the proposed provisions relating to incident reports and investigations, providers would be required to report, *inter alia*, incidents of “abuse,” “neglect,” and “exploitation.” See Proposed Sections 2380.17(a)(5)-(7), 2390.18(a)(5)-(7), 6400.18(a)(5)-(7), 6500.20(5)-(7). It does not appear, however, that the terms “abuse,” “neglect,” and

“exploitation” are defined. DRP urges DHS to include definitions of these terms.

b. Proposed Section 6100.46 addresses “[a]buse, suspected abuse, and alleged abuse of the individual,” requiring it to be reported in accordance with, *inter alia*, the Adult Protective Services Act (APS), the Older Adult Protective Services Act (OAPSA), and the Child Protective Services Law (CPSL); requiring it to be reported, *inter alia*, to DHS and the county; and prohibiting the alleged abuser from having contact with the individual until the investigation is concluded and it is confirmed that no abuse occurred. The protective services statutes extend not only to abuse, but also to neglect and exploitation. Moreover, providers have an obligation to protect their clients from neglect and exploitation as well as abuse. Accordingly, DRP strongly recommends that providers’ obligations under this provision be extended to cover neglect and exploitation as well as abuse.

c. Proposed Section 6100.803 requires supports coordinators, targeted support management and based-funded supports coordinators to report only what they directly observe. We believe this places individuals at significant risk. This seems to be a serious diminution of their current obligations to report incidents that are reported to them by others. See 55 Pa. Code 6000.912. This is a significant concern since SC’s may be the only un-conflicted person involved in the client’s life. If SC’s cannot report incidents about which they learn, but do not directly observe, there is a serious risk that the health and welfare of clients will be jeopardized. We object to this limitation and request that they be required to report (as is currently the case) all incidents reported to them or that they may become aware of through other means.

d. Proposed Section 6500.3 exempts Life Sharing homes, in private homes of relatives providing care – even those being paid to provide care - from all sections of the 6500 regulations. As such it does not require paid Life Sharing providers (who are related to the person receiving services) in those homes to report incidents of abuse, neglect, rights violations, etc. We have serious concern that this may place the individuals in those situations at grave risk. We strongly urge that anyone being paid to support an individual be required to report all allegations, known instances and suspected instances of abuse, neglect and rights violations.

#### **4. Individual Rights – Guardians**

In the proposed sections relating to individual rights (Sections 2380.21(f)-(g), 2390.21(f)-(g), 6100.181(f)-(g), 6400.31(f)-(g), 6500.31(f)-(g)), the regulations would provide that: (a) “[a] court-appointed legal guardian may exercise rights and make decisions on behalf of an individual in accordance with a court order”; and (b) “[a]n individual who has a court-appointed legal guardian, or who has a court order restricting the individual’s rights, shall be involved in decision making in accordance with the court order.” DRP has several concerns. First, “in accordance with the court order” may not place a sufficient burden on the provider to obtain the court order and limit the guardian’s participation to the scope of the court order. Second, the language does not reflect the guardian’s duties under Pennsylvania law, including the duty to respect to the greatest extent possible the individual’s expressed wishes and preferences; to assert his or her best interests; and to encourage the individual to participate to the maximum extent of his abilities in all decisions which affect him or her and to act on his or her own behalf whenever he or she is able to do so. 20 Pa.C.S.A. § 5521(a). Finally, the language does not support the individual to address situations when the individual’s guardian does not comport with his or her duties.

DRP proposes the following alternative language to the guardianship provisions:

A court-appointed guardian may limit the rights of the individual and make decisions for him or her only to the extent that the court order appointing the guardian authorizes the guardian to do so. It is the responsibility of the provider to: (a) secure a copy of and maintain in its files any guardianship order, and (b) review the guardianship order to determine which of the individual’s rights, if any, are limited by the order and which decisions, if any, the guardian may make in lieu of the individual.

If there is a conflict between the individual’s desires and the decision of his or her guardian, it is the responsibility of the provider to discuss with the guardian his or her duties under

Pennsylvania law to: (a) assert the rights of the individual; (b) assert the best interests of the individual; (c) respect the individual's preferences and wishes to the greatest extent possible; (d) encourage the individual to participate to the maximum extent of his or her abilities in decisions which affect him; and (e) encourage the individual to make decisions himself or herself whenever he or she can do so.

To the extent that the provider concludes that a court-appointed guardian is not acting in accordance with his or her duties or that the individual does not need a guardian, the provider must apprise the court which issued the order of its concerns and request a review hearing pursuant to 20 Pa.C.S.A. § 5512.2.

To the extent that the provider concludes that a court-appointed guardian's actions constitute abuse, neglect, or exploitation as defined by the Adult Protective Services Act, 35 P.S. §§ 10210.101-10210.704, or the Older Adult Protective Services Act, 35 P.S. §§ 10225.101-10225.5102, the provider will file a report with the appropriate agency.

## 5. Individual Rights – Protections

As stated above in Abuse, Neglect and Exploitation individuals receiving Life Sharing Services in the homes of relatives, even relatives who are paid caregivers, are exempt from the provisions of the 6500 regulations. As such individuals are not entitled to be made aware of their rights and to have their rights protected. While we certainly support the idea of individuals receiving services from family members and that those family members be paid to be caregivers, we cannot support the notion that the individuals receiving such services are not entitled to information about their rights or exercise of their rights. We urge that rights information and preservation of rights be provided in all settings.

## 6. Positive Interventions

a. The various proposed provisions relating to positive interventions all indicate that “physical protective restraint may be used only in accordance with § xxx(6)-(8) (relating to prohibition of restraints). See Sections 2310.154(b), 2390.174(b), 6100.344(b), 6400.194(b), 6500.164(b). While the reference to subpart (6) in prohibited restraints makes sense, the references to subparts (7) and (8) do not because they are outright prohibitions that include no exceptions. Clarification is in order.

b. The positive intervention provisions also state that an individual’s personal funds or property cannot be used to pay for damages inflicted by the individual unless the individual provides written, non-coerced “consent[] to make restitution for the damages.” See Section 2380.155(b), 2390.175(b), 6400.195(b), 6500.165(b). DRP objects to the inclusion of these provisions. In reality, it will be difficult to view any “consent” given in these circumstances as knowing and voluntary.

c. The positive intervention provisions require providers to have a “rights team” to review incidents of restraints, analyze systemic concerns, design positive supports, and discover the reasons for an individual’s behavior. See Section 2380.156, 2390.176, 6100.52, 6400.196, 6500.166. While DRP supports the idea of a rights team, we are concerned that the proposal is doomed to failure.

First, the rights team provisions allow each provider to use as its rights team “a county mental health and intellectual disability program rights team.” If many providers use that team in lieu of its own team, it will likely be overwhelmed and be rendered ineffective. More significantly, a county team will not have the first-hand knowledge of the individual and the program necessary to be effective. DRP recommends omitting that option.

Second, the rights team would only be required to meet one every three months. This would not afford prompt review of situations in which an individual has repeated incidents or use of restraints. DRP recommends that, in addition to quarterly meetings, the provider be required to convene a meeting of the rights team whenever an individual has more than three (3) incidents or suspected incidents of rights violations and/or use of restraints within one calendar months. The meeting should take place

within three (3) business days of the last actual or suspected rights violation or use of restraints.

Third, the proposed regulation (6100.52) makes it the responsibility of the rights team to “design positive supports as an alternative to the use of restraint”. We do not believe this is the role of a rights team, but instead should be delegated back to the individual’s team (including supports such as a behavior specialist) to develop positive support plans and submit that to the rights team for review.

## 7. Restraints

In various places in the proposed regulations manual restraints are defined as “... as a hands-on physical method that restricts, immobilizes or reduces an individual’s ability to move his arms legs, head or other body parts freely, on a nonemergency basis for more than 15-minutes within a 2-hour period. A manual restraint does not include physically prompting, escorting or guiding an individual to prove a support as specified in the individual’s PSP.” Formerly a manual restraint was defined as any hold that lasts more than 30 seconds. The proposed regulations seem to increase that to 15 minutes. We recommend the language be returned to 30 seconds with no restraint lasting more than 15 minutes in a 2 hour period.

## 8. Scope of Proposed 6100 Regulations

Section 6100.2(a) states that the regulations will apply to, inter alia, HCBS for individuals with autism provided through Section 1915(c) waivers. This would appear to encompass services provided to participants in the OBRA Waiver, many of whom have autism. Also, individuals with physical/medical diagnoses who are eligible for nursing facility care and are, or will be, served in OLTL waivers, including the new CHC waiver, sometimes have mild ID or autism as well. The Infants and Toddlers’ waiver also serves children with these diagnoses. DHS should clarify the application of these regulations to the OBRA Waiver and all the other waivers that may serve this population.

Section 6100.2(b) indicates that the regulations apply to, inter alia, state plan HCBS services for individuals with intellectual disabilities and autism. The definition of HCBS is so broad that it would encompass all MA-funded

services that are not specifically excluded. Such individuals may receive many state plan services (e.g., Applied Behavioral Analysis and other therapies, nursing, physician and dental care, residential care in 3800 licensed facilities). Some state plan services may be considered "vendor services", exempt from many of the regulations, but the definition of "vendor services" under 6100.806 is unclear. Does "directly enrolled" mean enrolled in the MA program or enrolled in a HCBS waiver program? DHS needs to clarify the application of these regulations to state plan services.

Section 6100.2(d)(8) indicates the regulations do not apply to individuals who are receiving services in PA, but who are from other states. As long as an individual is physically located in PA, receiving services in PA facilities where DHS has any oversight authority, it seems that PA should have oversight requirements/authority. Also, the lack of reporting on out-of-state residents could conceivably impact PA residents in the facilities. An incident involving an out-of-state resident could expose a threat to PA residents (e.g., if a staff abuses an out-of-state resident and PA knows about it and takes action, it will be protecting PA residents in the same facility; if it does not know about the incident, PA residents remain at risk). As a result we strongly urge DHS to write the proposed 6100 regulations in a manner that is inclusive of all people receiving services in covered PA programs, regardless of where they are from.

DRPs position regarding the scope of services for children is addressed below.

## **9. Children and Youth**

Children with ID and autism are covered by these regulations, yet their distinct needs are not addressed. First, children and youth are living in facilities covered by the 6400 regulations. For example, the Pediatric Specialty Care facility in Beaver County, which serves medically fragile children, is licensed under the 6400 regulations. Woods Services serves many children both in RTFs and in longer-term residences. A few years ago we met several children residing at Lynch Homes, a 6400 licensed facility primarily serving adults (which has since been bought out by Ken-Crest and may have changed.) 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. It is DRP's position that children should, whenever possible, be placed in families, but in any event should never be placed in long-term facilities that do not at least meet the new size requirements stated in the proposed 6100 HCBS regulations. We believe these regulations provide an opportunity to ensure permanency planning activities take place to enable children currently being raised in institutional settings to return to family life.

In addition, we have met children and youth with developmental disabilities other than ID and autism living in these same facilities funded by Medical Assistance who deserve the same protections, and who could benefit from the family homes provided under the 6500 regulations. These children are not served by the Office of Long-Term Living, or any other programmatic office unless they are adjudicated dependent. In fact, for some children whose parents care deeply but are unable to meet their children's special needs, access to Life Sharing could avoid the need to give up legal custody of their children. We encourage you to include these children under these regulations.

We read section 6100.2 to include 3800 licensed facilities under the scope of the proposed new regulations. This will provide an opportunity to apply permanency planning principles to begin to effectuate more family-based services for hundreds more children.

Finally, DRP strongly supports the inclusion of the new children's section of the regulations proposed by the Imagine Different Coalition in its comments to these regulations.

## **10. Communication**

Proposed Section 6100.50(b) states that individuals must receive "assistive technology necessary to effectively communicate." The Americans with Disabilities Act requires public accommodations, including social service providers, to offer auxiliary aids and services when necessary for effective communication. 42 U.S.C. § 12182(b)(2)(iii). "Auxiliary aids and services" is not limited to technology, but may also include, for instance, qualified readers and interpreters. Accordingly, DRP recommends the provision be revised to state: "The individual must be provided with auxiliary aids and

services and/or assistive technology necessary to effectively communicate.” For the same reasons, DRP recommends that proposed Section 6100.182, stating that “[a]n individual has the right to assistive devices and support to enable communication at all times” be modified to “[a]n individual has the right to auxiliary aids and services, including assistive devices and support, to enable communication at all times.”

Additionally, we recommend that language be added that makes it clear that the assistive devices, auxiliary aides, etc. must be maintained in working order (i.e. charged, fresh batteries, unbroken, etc.), that staff must have sufficient knowledge to assist the individual in using the devices/ aides, and that the devices/aids be available to the individual regardless of where the person may be (home, at work, in school, day program, medical appointment, etc.).

Proposed Section 6100.141/6100.142 should require the training related to Deaf culture and the unique needs of deaf waiver participants, identifying and serving deaf waiver participants, etc. that is specified in Harry M. Settlement Agreement ¶ 2e.

## **11. Physical Accessibility**

We believe Proposed Section 6100.442(b) does not go far enough to ensure physical accessibility for an individual. We suggest that DHS add language that requires all staff be trained in the use and maintenance of all mobility equipment and other assistive devices. Additionally, that key staff have information about where and by whom equipment/devices can be repaired in a timely manner and the authority to request such repairs to insure uninterrupted access to those supports to the greatest extent possible.

We also urge DHS to require that, whenever possible, a loaned device of similar or like kind be secured for the individual until the original equipment is repaired or replaced.

## **12. Person-Centered Planning**

a. Some of the proposed person-centered planning provisions (e.g., Sections 2380.184, 6100.222) omit the long-standing requirement that

individual plans must be subject to reevaluation at least annually and more frequently if necessary. The proposed provisions vaguely require that the PSP process must “[b]e timely in relation to the needs of the individual and occur at intervals, times, and locations of choice and convenience to the individual and to persons designated by the individual.” Absent mandated annual meetings, it is quite possible that the needs of individuals will not be periodically evaluated – especially those individuals who do not have actively involved families or advocates. Accordingly, DRP recommends that DHS mandate that meetings to review the PSP occur: (1) at least once a year, and (2) whenever there are events reflecting a possible change in needs (e.g., hospitalization, loss of or termination of services by a provider, police involvement) unless the individual does not want to have a meeting at that time.

b. The proposed regulations do not appear to impose any requirement on supports coordinators and targeted support managers to meet with the individuals (other than, perhaps at the PSP meetings). The current requirements that supports coordinators meet in person with the individual at least quarterly to assess their health and welfare and ensure that the ISP is being implemented, see 55 Pa. Code § 51.29, seem to have been omitted altogether. It is critical that DHS maintain the requirements that the supports coordinators have quarterly in-person meetings with the individuals to assure that an independent person check on their well-being and that they are receiving the services they need and to which they are entitled. Particularly in the case of individuals who have no close family or advocates, supports coordinators are the only independent and objective source of information.

c. Proposed Section 6100.222(b)(9) states: “Specify and follow guidelines for solving disagreements among the PSP team members.” These regulations need to be clear that if there is disagreement between the individual or his representative and the Supports Coordinator (SC), either the SC must include the services requested by the individual or his representative in the plan, or must issue a formal denial notice including an explanation of appeal rights. It should state that the participant need not sign his or her approval until he or she is actually satisfied that the plan will meet his or her needs and will be notified of appeal rights if the SC does not include the services requested by the participant in the service plan, or if the

state or its delegated entity (e.g., county or MCO) rejects an item in the service plan. Language must also be added to ensure that it is clear that a verbal denial made by a SC at any time, for any reason, is a denial that triggers appeal rights. The plan itself, or a written document provided with the plan, must include information concerning how to initiate an appeal process if the participant disagrees with any aspect of the plan. As a matter of due process, a denial of a service before a plan is submitted is just as much a denial as one issued in response to the plan.

d. In Proposed Section 6100.222(b) we recommend DHS add that all necessary auxiliary aids/services must be provided to ensure effective communication in the PSP process.

e. Proposed Section 6100.223(6) states that the PSP must identify the provider of each support. The PSP should list each support or service that the individual requests, regardless of whether a provider is currently identified, so that DHS may review the ISP and determine whether to authorize the support or service and that DHS is aware that the service or support is requested. There are times when it may take time to identify a willing provider. By waiting to include the support or service until a provider is identified, there may be a delay in authorization when a provider is identified. More significantly, it is important for DHS to be able to track how long it takes to identify willing providers.

f. Proposed Section 6100.223(9) should include the individual's communication mode, abilities and needs, including any supports or training needed to develop a mode of communication.

g. Proposed Section 6100.223(17) – Content of PSP – who decides what should be excluded, what is unnecessary or inappropriate? How is consent from individual or the person they designate secured?

h. Proposed Section 6100.342(6) should read “Communication needs, including any auxiliary aids and services required for effective communication.”

i. Proposed Section 6100.402 that states: "Necessary auxiliary aids and services will be provided to ensure effective communication between the incident investigator and the individual.

j. Proposed Section 6100.403(a). Add a section that reads "communication needs, including any necessary auxiliary aids and services."

k. Proposed Section 6100.669(a). Add a section that includes "costs of providing auxiliary aids and services, including qualified interpreters."

l. Proposed Section 6100.688. Add a section that states "The provider will assure that, if necessary, the contents of the room and board residency agreement is effectively communicated through the use of auxiliary aids and services.

m. § 6100.447. Facility characteristics relating to location of facility. Add: (e) With the approval of the Department's Deaf Services Coordinator or other designee, a waiver of the rules of this subsection may be granted to enable 8 or fewer participants with similar language needs to live within close proximity to each other if to do so would lessen the social isolation of the participants.

### **13. Employment**

Proposed Section 6100.262 requires that the individual have active and ongoing opportunities to seek and retain employment. This provision, however, does not take into account the possibility that older individuals with intellectual disabilities – like those without disabilities – may not want to participate in the workforce and may prefer other daytime activities. While work should be the default for working age individuals, those of retirement age should be given the opportunity to live as retired persons.

Section 6100.223 (11) – is overbroad. As written, employment would have to be sought before therapies, medical care, assistive technology, etc....., and would have to be sought for children and those or who no longer want to work. DRP recommends that it say something like, "Except in the case of children and retired individuals, active pursuit of competitive, integrated

employment as a first priority, before other alternative day programming is considered.”

#### **14. Education**

Proposed Section 6100.263 states that individuals should be able to participate in the following post-secondary educational programs if necessary for competitive employment: technical education; college and university programs; lifelong learning; and career development. DRP disagrees with DHS’s proposal to the extent that it limits funding for education to those courses and programs that are linked to development of employment skills. People with intellectual disabilities should have the same opportunities to pursue education for the sake of learning as those without intellectual disabilities. In addition, DRP strongly urges DHS to include Transition Post-Secondary Programs for Individuals with Intellectual Disabilities and Autism, which are associated with colleges and universities, in the list of approved post-secondary education programs. Those Transition programs offer individuals with intellectual disabilities access to college campuses and interaction with college students to which they might not otherwise have access and the opportunity to learn skills that will enable them to live independently and to secure competitive employment.

#### **15. Transition**

Proposed Sections 6100.303, 6100.304(b), and 6100.305, respectively, indicate the circumstances under which a provider can choose to terminate an individual’s services, require the provider to give at least 45-days’ notice prior to the date of the proposed termination, and state that the provider must continue to provide services until a new provider is located unless otherwise directed by DHS. DRP suggests that DHS include a requirement that a PSP meeting be held prior to any termination to determine whether additional or different supports might enable the individual to remain in the program.

Proposed Section 6100.303(2) addresses transfer or discharge when a person’s needs cannot be met due to a change in need. We suggest that the regulations require that home modifications to make the home accessible be a consideration prior to the determination to transfer or discharge.

Proposed Section 6100.303(3) – add, “but only if a failure to accommodate would not violate the Fair Housing Act or the Americans with Disabilities Act.”

Proposed Section 6100.304(a) – DRP strongly recommends that the provider be required to give at least 90 days' notice considering that even an uncontested discharge of a person, who requires readily available supports, often takes at least that long to put into place.

#### **16. Conflicts of Interest**

Proposed Section 6100.53 merely requires that providers develop and implement a conflict of interest policy, but offers no guidance whatsoever on the parameters of such a policy. This is inadequate. DRP recommends maintaining the basic standards in the current rules, 55 Pa. Code § 51.33.

#### **17. Medication Administration**

Additionally referenced earlier, individuals receiving Life Sharing Services in the homes of relatives - even relatives who are paid caregivers - are exempt from the provisions of the proposed 6500 regulations. As a result, individuals receiving Life Sharing Services in those cases are not entitled to paid caregivers who are trained in the administration of medications. Paid caregivers who are relatives, despite the fact that they are providing Life Sharing services in their homes, should be required to successfully complete the medication administration training. We urge DHS to provide this vital safeguard to protect the health and safety of individuals.

#### **18. Individual Records**

Nothing in the proposed regulations requires that a record containing all information necessary for all staff to adequately support individuals - current ISP, health records, behavior plan and data collected, specialized evaluations or documents including ELP, biographical timeline, social/developmental history, etc. - be available at each location where the person receives services (residence, day program, etc.). In far too many instances providers prefer to keep all that information in a centralized location (main office) leaving staff at the on-site location without needed documents/information to adequately understand why people need specific

supports. This can create a health and safety problem for the individual. We suggest that DHS specify which records need to be on-site and available to all staff at the location where the services are delivered.

## **19. Life Sharing**

Proposed Section 6500.4(iii) - definition of Life sharing home or homes – allows for relatives (with no limit on number) to live in the life sharing home and also allows up to an additional 4 unrelated people to live there as well. We are concerned, based on experience, about the number of people who could potentially be living in one of the homes. We have encountered extremely large extended families living in homes where there were not enough bedrooms for everyone living in the home so people sleep in the living areas of the home making them unusable for anything else. In a few cases this has caused the living environment to be unsafe from both a physical (overcrowding) perspective as well as an emotional well-being perspective. Although we understand that this can be a cultural issue and one that is very sensitive to address, we believe strongly that there must be some limit placed on the number of people living in a home. Perhaps the limit could be based on the number of bedrooms and an allowable number of occupants per bedroom. Additionally, it is our understanding that more than 3 unrelated people living in an unlicensed home where services are provided could be considered an illegal personal care home.

## **20. Families**

Throughout the varying proposed regulations there are references to the involvement of families. Although generally, this is a good idea, there must be clearly delineated protections for individuals who do not wish their families to be involved in their lives or for whom family involvement poses a substantial risk (history of abuse/neglect, denial of rights, etc.). We strongly urge that all references to people involved in the person's planning, meetings, life, etc. be phrased as "at their direction, or as demonstrated to be their desire by their behaviors/actions". If it is determined that the family presents a health or safety risk to the individual, DHS must take appropriate steps to remedy that risk.

## **21. Other issues**

Section 6100.45 – “family member designated by ...” The use of “family member” is confusing in the proposed regulations since only “family” is defined. “Family member” could be construed as more narrow than “family,” which is the term defined in Section 6100.2. Additionally, DHS should be clear that this is not the person’s family - unless the person wants them involved - but is a family member of a person with a disability who is serving at the request of the managing entity.

Section 6100.52 – DHS should remove family as a required member of the rights team as the individual may not want them involved.

Section 6100.54 – Please add “or as is required by law.”

Section 2380.35 – requires at least one direct service worker for every 6 people be present with individuals at all times except while staff are attending training or meetings. We strongly urge DHS to change this requirement to reflect the level of staffing required by an individual’s PSP be available to that person at all times. Training or meetings are not acceptable reasons to reduce an individual’s documented staffing level needs.

Section 2380.173(1)(iv) and 6400.213(IV) and 6500.182(iv) – change to “and/or cultural affiliation”.

Section 2380.173 (1)(v) – define “current”.

Section 2390.5 Definition of “disabled adult” – please use person first language. Use instead –“Adult with a Disability”. “Handicapped employment” – use instead “employment for a person with a disability” or a similar term that promotes person first language.

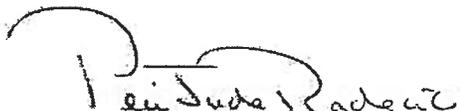
Section 2390.124 – Simply state this as the name, address and telephone number of the designated contact in case of an emergency. This would more clearly allow the person to indicate who they want contacted which may be none of those currently listed in the proposed regulations.

Julie Mochon  
December 19, 2016  
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Section 2390.155 – add number 14 to specify the inclusion of any court order or guardianship order.

If you have any questions, please contact me.

Sincerely,



Peri Jude Radecic  
Peri Jude Radecic  
Chief Executive Officer

CC: Nancy Thaler  
IRRC