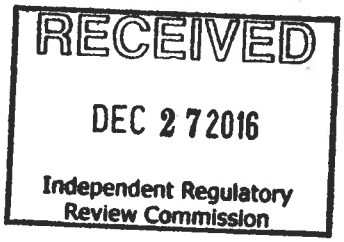
3160 14-540 (267)

Kroh, Karen

From:	Mochon, Julie
Sent:	Wednesday, December 21, 2016 8:43 AM
To:	Kroh, Karen
Subject:	FW: Comments on Home and Community-Based Supports and Licensing Proposed Rulemaking, Regulation No. 14-540
Attachments:	The Arc of PA Comments 12.20.2016.pdf

From: Maureen Cronin [mailto:mcronin@thearcpa.org]
Sent: Tuesday, December 20, 2016 4:17 PM
To: Mochon, Julie
Cc: Thaler, Nancy
Subject: Comments on Home and Community-Based Supports and Licensing Proposed Rulemaking, Regulation No. 14-540



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Dec. 20, 2016

Ms. Julie Mochon, Policy Specialist
Office of Developmental Programs
Room 501, Health & Welfare Building
Harrisburg, PA 17120

RE: Comments on Home and Community-Based Supports and Licensing Proposed Rulemaking, Regulation No. 14-540

Dear Ms. Mochon:

The Arc of Pennsylvania is a statewide nonprofit organization that provides advocacy and resources for citizens with intellectual and developmental disabilities and their families. It was established in 1949 and currently includes 34 chapters in 57 counties and over 8,000 members across Pennsylvania. The Arc is a grassroots, member-driven organization led by people with disabilities and their families. Local chapters provide services and advocacy for individuals with intellectual and developmental disabilities and their families and most of our chapters provide services as well.

Thank you for the opportunity to comment on the Home and Community-Based Supports and Licensing proposed regulations. The Arc of Pennsylvania appreciates The Office of Developmental Program's (ODP) commitment to stakeholder input that including individuals and their families. Our organization had representation from local chapters and the state chapter at the nine stakeholder meetings held from February to August of 2015. The comments below represent the input of both local chapters and the state chapter. The Arc's core priority is protecting and enhancing the rights of individuals with intellectual and developmental disabilities; the following comments stem from this commitment.

General Comments

While we appreciate ODP's need to ensure that regulations align with waiver applications and submission timelines for CMS, completing a thorough analysis of the entirety of the proposed regulation changes is implausible for many stakeholders particularly individuals and families. To provide comprehensive and sufficient analysis of the regulations within the given timeframe, our comments primarily focus on Chapter 6100. Our comments are meant to apply to relevant sections of Chapters 2380, 2390, 6400 and 6500.

We applaud the Office of Developmental Programs (ODP) for ensuring the proposed regulations use consistent language and requirements across all chapters. The Arc of Pennsylvania supports repealing Chapter 5100 and amending portions of the four chapters to reduce duplication and administrative burdens.

Additionally, The Arc of Pennsylvania enthusiastically supports the proposed limits on the use of restraints to only emergency situations. The use of restraints has a disturbing history of harming individuals with intellectual and developmental disabilities, restricting their rights and choice in their own homes and communities.

Increased Administrative Burden and Cost

The Arc of Pennsylvania is concerned that the proposed regulations do not meet the Office of Developmental Program's stated goals of streamlining processes and eliminating duplication; the breadth and number of the proposed regulations appear to create a more cumbersome system. We understand ODP's interest in increasing the number of service models that do not require licensing. We recommend focusing less on creating flexible service models that are not licensed but rather streamline already existing regulations to promote quality while protecting individuals. Many of the regulatory updates are overly prescriptive and include components that are more reflective of best practices than concrete regulatory requirements.

Since each of the new regulations will become a discrete activity that must be monitored and documented for compliance, the added expectation to proactively prove compliance in these regulations will result in excessive documentation for providers. The Arc of Pennsylvania is concerned that a heavier administrative burden will detract from providers' ability to offer person-centered services.

The Arc of Pennsylvania recommends that small providers not have the same compliance requirements as large providers. As a statewide advocacy and provider organization, we are connected with providers who range significantly in size - some serve a small number individuals in a year and others serve hundreds. We are concerned that, since these regulations will apply to all providers in the Commonwealth regardless of size, smaller providers will be forced to cut services and increase administrative activities to meet the increased compliance requirements. We recommend that ODP implement compliance requirements that are commensurate with the number of waiver services so that smaller providers can prioritize providing person-centered services instead of being unfairly burdened with additional administrative requirements.

Furthermore, The Arc of Pennsylvania expects that if the proposed regulations are approved as written they will result in more cost to the Commonwealth. The Department of Human Services already incurs significant costs to ensure compliance of current regulations; the proposed regulations would only increase these costs. The proposed regulations also appear to have significant fiscal impacts to providers of Agency with Choice, which provide a more cost-effective model in which individuals

direct their own services. The proposed training requirements will create impractical obligations for individuals who use or are interested in using Agency with Choice and will lead to individuals and families choosing higher-cost licensed services.

Language That Reflects Inclusion

As The Arc of Pennsylvania, we know that language matters. It reflects and shapes attitudes, which is one reason The Arc has been a leading proponent of ending use of the outdated and hurtful "r-word". Considering the decades that these regulations may be in effect, The Arc of Pennsylvania recommends the following wording changes throughout the proposed regulations.

The Arc of Pennsylvania proposes that, considering the intent of Medicaid funding to ensure people with disabilities have a comparable quality of life to their peers, the term "supports" be taken out and replaced with the word "services." While "supports" has been the preferred term in recent years, in today's political climate regarding publicly funded programs, the word "services" better reflects the more professional work being done on behalf of individuals with intellectual disability and autism.

The proposed regulations use the pronouns he/his/himself several times. The Arc of Pennsylvania recommends that ODP instead use pronouns that are inclusive of the many ways that individuals identify their own gender. Instead of he/his/him/himself, we recommend using the pronouns they/theirs/them/themselves.[1]

Finally, the format and organization of the proposed regulations is confusing to people with disabilities and their families. This excludes the individuals most impacted by these regulations from contributing and commenting on them. For future iterations of these proposed regulations; The Arc of Pennsylvania recommends that ODP create a plain-language version of the regulations and distribute them to allow individuals with disabilities and their family members to offer their own perspective on this important document.

Children in Congregate Settings

We strongly support the Office of Developmental Program's intent to broaden eligibility to include young children so that children currently in large residential settings can be served in their community. The proposed regulations are aligned with the needs of adults and do not reference children services. Considering this, Chapter 6100 regulations should be thoroughly reviewed and revised to accommodate serving young children. Priorities should include:

[1] While many all-gender pronouns exist, we recommend these based on pronoun guidance from Trans Student Educational Resources at www.transstudent.org/pronouns101.

- Revising Chapter 6100 to include concrete permanency planning for children; for example, permanency should be included in person-centered planning.
- The rights section should be revised to reflect the developmental needs of children.

Suggested Line-Item Changes in Regulations (our recommendations are in blue):

CHAPTER 2380. ADULT TRAINING FACILITIES GENERAL PROVISIONS

§ 2380.3. Definitions.

- Definitions should be the same across all chapters.

- The term "direct service worker" is used here and "direct support professional" is used elsewhere in the regulations. Consistency is needed across regulations.

§ 2380.17. Incident report and investigation.

(a) *Our comment:* Reportable incidents should be the same across all chapters.

§ 2380.33. Program specialist.

- All qualifications across all regulations should be the same as the waiver qualifications for positions.

- Add: (4) which allows documented years of experience and no degree (this should be added for all positions and across all regulations).

§ 2380.36. [Staffing] Emergency training.

(c) There shall be at least **[one]** 1 staff person for every 18 individuals, with a minimum of **[two]** 2 staff persons present at the facility at all times who have been trained by an individual certified as a trainer by a hospital or other recognized health care organization, in first aid, Heimlich techniques and cardio-pulmonary resuscitation within the past year. If a staff person has formal certification from a hospital or other recognized health care organization that is valid for more than 1 year, the training is acceptable for the length of time on the certification.

- Use current procedures and terminology with American Red Cross and Heart Association.

§ 2380.183. [Content of the ISP.] The PSP team.

- Include approved non-comparative assessments that identify skills, interests and supports that may assist the individual toward a goal of greater independence and community-integrated employment.

CHAPTER 2390. VOCATIONAL FACILITIES GENERAL PROVISIONS

§ 2390.5. Definitions

"Handicapped employment" - A vocational program in which the individual does not require rehabilitation, habilitation, or ongoing training to work at the facility.

- Is this definition still needed?

§ 2390.33. Program specialist.

(a) *Our comment:* Program specialists' ratio should be per agency, not facility, to avoid having one individual with multiple program specialists from same agency, consider 1:20 ratio due to increased reporting requirements.

(b)(4) Supporting the integration of individuals in the community, including support and planning support to achieve the individual's goal(s) to work in community integrated settings.

§ 2390.153. [Content of the ISP] The PSP team.

(b) *Our comment:* Having at least 3 members of the PSP team attend the PSP meeting is not always realistic. Some individuals have no family or service providers and the meeting is held with the Supports Coordinator and the individual. This comment is also applicable to the same language in the 2390, 6400 and 6500 regulations.

CHAPTER 6100. SUPPORT FOR INDIVIDUALS WITH AN INTELLECTUAL DISABILITY OR AUTISM

§ 6100.1. Purpose.

- Base funded services are included in this chapter and the *Summary of Major Revisions* states that the 4300 regulations are applicable for base funded services. This reference should be amended to assure that counties do not set rates under the 4300 regulations when there is already a state set waiver rate for that same service for the providers.

§ 6100.2. Applicability.

(b) This chapter applies to State plan HCBS for individuals with an intellectual disability or autism.

- Department needs to broadly disseminate the State plan.

- This section does not reflect ODP's intent to include children from birth through seven years of age that have a developmental delay but are not diagnosed with intellectual disability and or autism in the waiver.

- We support that in 6100.2.(9), the vendor fiscal employer agent model was removed from this chapter.

- We recommend the removal of Agency with Choice (AWC) and Organized Health Care Delivery Services (OHCDS) from the chapter so all administrative services are provided without the extensive and irrelevant requirements of this chapter. Administrative Entity and Vendor Fiscal services are not included in the chapter, therefore, the AWC and OHCDS administrative services should not be included. A separate agreement for administrative service providers would assure proper administration without unnecessary regulatory burdens.

§ 6100.3. Definitions.

"*Natural support*" - ~~An activity~~ A person or persons who provide or assistance that is provided voluntarily to the individual instead of reimbursed support.

"*Support*" - Change to "service" that is funded through a waiver.

- All definitions for these regulations should be included in chapter 6100.3, and the applicability of chapter 6100 definitions should be noted in each of the subsequent regulatory chapters.

- The following is a list of definitions that should be included in this chapter, and further consideration of a comprehensive list of definitions should be considered:

- Abuse

- Agency with choice *(Include only if AWC remains in the regulations, however we recommend removal of AWC from the regulations as previously noted.)*
- Conflict of interest
- Corrective action
- Dangerous behavior
- Designated managing entity
- Directed corrective action plan
- Exclusion
- Exploitation
- Incident
- Individual
- Lead designated managing entity
- Natural support
- Neglect
- Organized health care delivery service (OHCDS) *(Include only if OHCDS remains in the regulations, however we recommend removal as previously noted.)*
- Person-centered support plan (PSP)
- Physical restraint
- Positive Intervention
- Chemical restraint
- Dangerous behavior
- Mechanical restraint
- Physical restraint
- Pressure point techniques
- Provider
- Remediation action plan
- Restraint
- Seclusion
- Service (remove "Support")
- Voluntary exclusion
- Vacancy factor
- Volunteer (providing HCBS)

§ 6100.41. Appeals.

- Recommend changing "Chapter 41" to "Pennsylvania Code Chapter 41" for clarification. This section should address all bases of appeals and clarify procedures for appeals by individuals and providers.

§ 6100.42. ~~Monitoring compliance~~ Review of Provider Performance.

- This section should not be duplicative of other licensing regulations and should ensure a coordinated effort such that audits, fiscal reviews and monitoring assessments are not redundant or duplicative.

- This section should also state that regularly scheduled monitoring assessment will be coordinated by a lead designated managing entity and not multiple designated managing entities if the provider encompasses multiple areas. This will also aid in the reduction of costs associated with multiple designated managing entities having to schedule and come for on-site reviews, including reduction in time and travel costs.

(a) The Department and the designated managing entity may monitor compliance with this chapter at any time through an audit, provider monitoring or other monitoring method.

- This is far reaching. The regulation should describe scheduling/frequency of monitoring unless there is cause for additional monitoring.

- While the department should periodically monitor performance of Lead Designated Entity, monitoring should generally be limited to only one monitoring entity.

(b) *Our comment:* Recommend deleting this paragraph, it is too vague.

(c) The provider shall cooperate with the Department and the designated managing entity and provide the requested compliance documentation in the format required by the Department ~~prior to, during, and following an audit, provider monitoring or other monitoring method~~.

- Combine (c) & (d)

(e) The provider shall complete a corrective action plan for a ~~violation~~ non-compliance or an alleged ~~violation~~ non-compliance of this chapter in the time frame required by the Department.

- Within 45 days unless there is a health/safety reason for expedition.

(g) *Our comment:* Recommend changing "violation" to "non-compliance".

(1) *Our comment:* Recommend changing "educational" to "training".

§ 6100.43. Regulatory waiver.

(e) *Our comment:* Allow for shorter timeframe if agreed to by all parties.

§ 6100.44. Innovation Project.

(a) A provider may submit a proposal to the Department to ~~demonstrate~~ implement an innovative project ~~on a temporary basis~~.

- An innovation project may not always be temporary but should still have relief from these regulations.

§ 6100. 45. Quality management.

(b)(5) *Our comment:* We support the inclusion of individual and family satisfaction surveys, as well as informal comments.

- This section is overly prescriptive, listing activities that may be valuable but are not relevant to every service. The unintended consequence is that providers will spend time developing documents proving compliance with each requirement in areas that will not impact quality services for individuals. Tracking progress, reviewing trends, and analysis of training outcomes are all good practices but the logistics of providers demonstrating that these activities were completed will result in writing more about quality than assuring quality. We are pleased to see that AWC was removed from this section while still recommending that AWC be removed from the chapter. OHCDS and Vendor Fiscal service providers should also be excluded from this section.

(b) *Our comment:* too prescriptive

(b)(1) to (9)(e) *Our comment:* Suggested areas of review are not required.

§ 6100.46. Protective services.

(a) Abuse, suspected abuse and alleged abuse of an individual, regardless of the alleged location or alleged perpetrator of the abuse, shall be reported and ~~managed~~ addressed in accordance with the following:

(c) *Our Comment:* We suggest that "Family" be added to the list of those persons who are notified of abuse.

(c)(4) & (5) *Our comment:* Use either managing entity or county government, but not both.

- Revise notification in (c) to align with the current Incident Management policy notification requirements. Generally, an alleged abuse would not be reported immediately.

§ 6100.47. Criminal history checks.

(b)(1) *Our comment:* Change to HCBS paid household members.

(b)(5) *Our comment:* Delete volunteers, regulations should apply to those providing HCBS services.

- Distinguish between volunteers providing HCBS and volunteers/friends in the community. E.g. volunteers/friends taking the individual to church should not be required to have criminal history checks.

§ 6100.50. Communication.

(a) *Our Comment:* For written forms of communication, ODP should provide all required forms and documents in other languages and supplemental funding for translation.

- AWC should be excluded.

§ 6100.51. Grievances.

(a) The provider shall develop procedures to receive and document~~, and manage~~ grievances.

- Define or give examples of grievances and limit to grievances on by or on behalf of an individual.
- This should not include personnel grievances.

(c) The provider shall address ~~permit and respond to~~ oral and written grievances from any source, including an anonymous source regarding the delivery of services ~~the delivery of a support~~.

(g)(5)&(6) *Our comment:* Should be combined.

- Providers should not be required to respond to an anonymous source.

(h) *Our comment:* Some issues take longer than 21 days to resolve.

- Add right to elevate grievance to managing entity or beyond if not satisfied with resolution of grievance.

- The individual and their family must be provided information regarding the process to submit complaints and grievances to the administrative entity and the Department; in addition to, the process for submission against the provider. While grievances should first be resolved at the provider level, if they are not, individuals and their families need to know where else to voice their grievances.

§ 6100.52. Rights team.

(e) If a restraint was used, the individual's health care practitioner ~~shall be consulted~~ should be consulted if there is a risk to their health.

- The "Rights Team" responsibilities should be incorporated into the Incident Management team's responsibility to avoid duplication of effort.

- The work of rights teams is duplicative of other committees including the individual's PSP team. The requirements are confusing especially considering the membership of the committee. How would this team meet regarding specific individuals yet meet quarterly? This section is not appropriate for AWC and other unlicensed providers. This regulation is an example of requiring far more than necessary from agencies providing a small amount of waiver services especially if they do not allow restrictive interventions.

§ 6100.53. Conflict of interest.

(c) An individual or a friend or family member of an individual who is supported by the provider may serve on the provider's governing board.

- We strongly support having individuals and family members serve on the governing board.

§ 6100.55. Reserved capacity.

- The Arc strongly supports an individual's rights to return home after hospitals and rehabilitation, but this requires sufficient funding to allow a provider to hold a vacancy.

§ 6100.81. HCBS provider requirements.

- For clarity, separate this section into new HCBS provider requirements and existing provider requirements.

§ 6100.82. HCBS documentation.

- Add: (8) Has a free choice of any willing and qualified provider.

§ 6100.85. Ongoing HCBS provider qualifications.

(d)(1) *Our comment:* What is a "system for award management"?

§ 6100.141. Annual training plan.

- While this section would be appropriate for larger providers with training departments, providers of a relatively small number of waiver services would be challenged to meet every requirement in this section. Also, requiring copies of certifications received is excessive.

§ 6100.142. Orientation program.

- The Department should assist in providing trainings on required information so that each provider does not should develop its own curriculum for statewide requirements. For example, the Department should develop curriculum regarding recognizing abuse and neglect. Again, this section appears to be geared towards licensed providers and is counter-productive to supporting unlicensed provider's family support models and AWC providers.

- Orientation requirements should be different for direct support professionals and ancillary staff. For example, (b)(1) should not apply to ancillary staff. Ancillary staff training should focus on mandated reporter training within 30 days of hire.

(a)(6) *Our comment:* Same comment as 6100.47; We recommend limiting this to those providing HCBS, this requirement should not apply to those providing natural supports.

- We recommend removing AWC, OHCDS and Vendor services from this section.

§ 6100.143. Annual training.

- There should not be a time requirement for training. Also, having very prescribed training requirements negate the need for a training plan. Providers should either develop a training plan or follow the requirements in this section, not both.

(a)(1) The following persons shall complete twenty-four (24) hours of training each year:

- Not AWC, vendor fiscal and other unlicensed programs.

(b)(3) *Our comment:* Reimbursed services should not be done by volunteers.

(c)(1) to (c)(4) *Our comment:* We support having these four core areas, and we also recommend ODP offer online courses.

§ 6100.181. Exercise of rights.

(g) *Our comment:* We support the clarification of the types of guardianships and individual's rights.

§ 6100.182 Rights of the individual

- Reference value statement from *Every Day Lives*.

(b) ~~An individual has the right to civil and legal rights afforded by law, including the right to vote, speak freely, and practice the religion of his choice or to practice no religion.~~ An individual has the right to the same civil legal, and human rights afforded by law to all people.

(m) An individual has the right to assistive devices and ~~supports~~ services to enable communication at all times.

§ 6100.183 Additional rights of the individual in a residential facility

(b) An individual has the right to unrestricted access to send and receive mail and other forms of communications including electronic, unopened and unread by others.

§ 6100.185 Informing of rights.

(a) The provider shall inform and explain individual in a manner and language preferred by the individual ~~rights to the individual~~, and persons designated by the individual, upon entry into the program and annually thereafter.

§ 6100.186. Role of family and friends.

- Much of this section is more appropriate for residential or life sharing services. While this is critical for individuals, we are concerned that monitoring compliance could turn into even more documents needed to be produced during monitoring.

- We recommend making training in the PSP process (including philosophy, best practices, and the content/format requirements of the PSP) available to individuals with disabilities and their families. This could be a prime opportunity to utilize the Person Centered Training (PCT) trainers.

- We recommend that individuals with disabilities and their families be informed of their right to self-direct their service(s) when entering the system and annually by their Supports Coordinator.

§ 6100.221. Development of the PSP.

(e) The PSP shall be revised at least annually when an individual's needs or support system changes and upon the request of an individual or a member of the team.

- Not all revisions are the result of an assessment

(d) The initial PSP shall be developed prior to the individual receiving a reimbursed support except for supports coordination activities that are completed in advance of the PSP.

§ 6100.222. The PSP Process.

(7) *Our comment:* Including translation/interpretation for English as a second language.

(8),(9),(11) *Our comment:* These are examples of best practices that should not be regulations requiring written documentation to prove compliance. However, for (9) there should be a description of how to resolve differences between the individual/ their representative and the PSP team that include appeal rights.

§ 6100.223 Content of PSP

- This section is in conflict with the *Everyday Lives Values in Action's Recommendation* to simplify the PSP process. While listed components should be considered at the meeting, they should not all be required to be included in the PSP contents.

(3) The individual's goals and preferences related to relationships, community participation, employment, income and savings, health care, wellness, education, house, living arrangements, and independence.

(10) *Our comment:* Opportunities could be endless and changing each week so not appropriate to be required in the PSP.

(11) *Our comment:* The Arc of Pennsylvania fully supports this language and the focus on employment for participants in the waiver program. We recommend that some

groups of individuals be allowed to omit this requirement; for example, young children and individuals who are already of retirement age.

(12) Education and learning history and goals.
- Too broad. Medical and educational history should be maintained in the individual file rather than PSP.

(16) The individual's choice of the provider(s) and setting(s) in which to receive supports.

(18) Financial information, including how the individual chooses to use and manage personal funds.
- Too broad to be a required content in the PSP.

(19) A back-up plan to identify a needed support as identified by the PSP team if the absence of the designated support person would place the individual at a health and safety risk.
- This is redundant of provider's requirement for back-up plan.

(21) *Our comment:* This is a dated regulation with electronic approvals/signoffs that will replace signatures.

§ 6100.224. Implementation of the PSP.

The provider(s) identified in the PSP shall implement the PSP, including revisions.

- Timelines for implementing the plan including the start of services should be identified on the plan.

§ 6100.225. Support coordination and TSM.

- Combine 6100.221(e) into 6100.225.

§ 6100.226. Documentation of support delivery.

(e)(6) The outcome of the support delivery.
- Too nebulous, better to address in three-month review.

(f) The provider, in cooperation with the supports coordinator or the targeted support manager and the individual, shall complete a review of the documentation of support delivery for each individual, every three (3) months~~, and document the progress made to achieving the desired outcome of the support provided~~.

- For those with very significant disabilities, there needs to be an acknowledgement that HCBS can also be used to maintain skills rather than progress always being expected.

- Thank you for allowing quarterly progress notes.

§ 6100.261. Access to the community.

(a) The provider shall provide the individual with the support necessary to access the community in accordance with the individual's PSP.

- We strongly support access to the community with commensurate funding.

§ 6100.262. Employment

(a) *Our comment:* This should include exceptions for children and senior citizens.

(b) Authorization for a new prevocational support for an individual who is under 25 years of age shall be permitted only after a referral is made to the OVR and the OVR either determines that the individual is ineligible or closes the case.

- This leads to unnecessary delays.

(c) At the annual PSP revision, the individual shall be offered appropriate opportunities related to the individual's skills, ~~and~~ interests, conditions for success, and encouraged to seek competitive, integrated employment.

- How will "appropriate opportunities" be defined to ensure that participants are being offered genuine opportunities for community integrated employment without being limited by perceived limitations?

§ 6100.263. Education.

- Will there be limits to the amount of money used for education?

§ 6100.303. Reasons for a transfer or a change in a provider.

(a)(2) The individual's needs have significantly changed, advanced or declined so that the individual's needs cannot be met by the provider, even with the provision of supplemental supports, home modification and needing funding.

- Individuals should never have to move because insufficient funds were not afforded to support the individual.

§ 6100.304. Written notice.

(a) If the individual chooses another provider, the PSP team shall provide written notice to the following at least thirty (30) days prior to the transition to a new provider or sooner if agreed by all parties:

(b) If the provider is no longer able ~~or willing~~ to provide a support for an individual in accordance with § 6100.303 (relating to reasons for a transfer or a change in a provider), the provider shall provide written notice to the following at least forty-five (45) days prior to the date of the proposed change in support provider or transfer:

(c)(3) The support that the provider is unable ~~or unwilling~~ to provide or for which the individual chooses another provider.

(c)(5) The reason the provider is no longer able ~~or willing~~ to provide the support as specified in § 6100.303.

§ 6100.307. Transfer of records.

(a) The provider shall transfer a copy of the individual record to the new provider at no cost to the individual prior to the day of the transfer.

POSITIVE BEHAVIOR INTERVENTION

§ 6100.341. Use of a positive intervention.

"*Positive Behavior Interventions/Supports*" - An action or activity intended to prevent, modify and eliminate a dangerous behavior. This includes use of trauma informed care, improved communication, reinforcing appropriate behavior, an environmental change, recognizing and treating physical and behavioral health symptoms, voluntary physical exercise, wellness practice, redirection, praise, modeling, conflict resolution, and de-escalation.

§ 6100.343. Prohibition of restraints.

- We strongly support the prohibition of restraints unless there is a severe threat to the individual's safety or others.

§ 6100.344. Permitted interventions.

(b) A physical protective restraint may be used only in accordance with § 6100.343(6) -(8) (relating to prohibition of restraints).

- This is confusing. Is a physical protective restraint a manual restraint?

(d) A physical protective restraint may only be used in the case of an emergency to prevent an individual from injuring the individual's self or others.

- List first.

(f) A physical protective restraint may not be used for more than 15 minutes within a 2-hour period.

- Within a 2-hour period connotates programmatic restraint rather than restraints only used in dire emergencies.

§ 6100.345. Access to or the use of an individual's personal property.

- Delete § 6100.345 (b)(1) -(3). This section is too likely to be abused.

§ 6100.401. Types of incidents and timelines for reporting.

- Delete (a)(3).

(a) (16) A medication administration error, including prescription and over the counter medication administration error.

- Incident reporting should occur for significant prescription and over the counter medication errors that impact the health and safety of the individual.

§ 6100.442. Physical accessibility.

(a) *Our comment:* Regulation should require compliance with the Americans with Disabilities Act.

(b) *Our comment:* Regulation should assure that all mobility equipment and other assistive devices are not only available but are maintained. Far too often individuals wait endlessly for their equipment to be repaired and returned. Back up plans should assure availability of replacement or loaned equipment until the original equipment is repaired or replaced.

§ 6100.446. Facility Characteristics relating to size of facility.

- We support smaller settings but do not believe that size is the only demarcation of whether a setting provides quality person-centered services.

- Larger facilities have benefits that we hope to see carried over to smaller settings, including: individuals interacting with multiple staff on a daily basis (which provides accountability and helps prevent abuse) and facility capacity for varied activities which gives individuals some choice and independence. Again, we support smaller settings and note they must have commensurate funding to ensure services provided in these settings offer individuals with disabilities choice and safety.

(b) A residential facility that serves primarily persons with a disability, which is newly funded in accordance with this chapter on or after _____ (*Editor's Note:* The blank refers to the effective date of adoption of this proposed rulemaking.), may not exceed a program capacity of four.

- We generally support a capacity of four but there are circumstances where individuals choose to live with seven others to afford more flexibility and independence.

(b)(1) *Our comment:* Enforcing a capacity of four eliminates any possibility of any side-by-side living arrangements.

(b)(2) *Our comment:* Currently, side-by-side living arrangements have facilitated those needing minimal support to have access to staff nearby.

§ 6100.447. Facility characteristics relating to location of facility.

(a)(4) A nursing facility.

- CMS allows for an exception if indicated.

§ 6100.462. Medication administration.

(b)(2) *Our comment:* Unlicensed providers cannot be required to allow employees to administer medications, especially given there is no training available or approved by the Nursing Board for unlicensed providers.

§ 6100.463. Storage and disposal of medications.

(b) A prescription medication may not be removed from its original labeled container more than two (2) hours in advance of the scheduled administration.

- This is challenging for those in community integrative activities.

§ 6100.465. Prescription medications.

(e) Changes in medication may only be made in writing by the prescriber or, in the case of an emergency, an alternate prescriber, except for circumstances in which oral orders may be accepted by a registered nurse and licensed practical nurse in accordance with regulations of the Department of State. The individual's medication record shall be updated as soon as written notice of the change is received.

- Provisions should be allowed for electronic prescriptions.

§ 6100.468. Adverse reaction.

- Include to be documented in PSP.

§ 6100.469. Medication administration training.

- If medication administration training is required for unlicensed programs, the training should be made available to unlicensed program staff.

§ 6100.482. Payment.

(d) If an HCBS is payable under a third-party medical resource, the provider shall bill the third-party medical resource in accordance with §1101.64 (relating to third-party medical resources (TPR)) before billing a Federal or State-funded program and provide documentation.

(f) The provider shall document ~~third-party~~ medical resource claim submission and denial for an HCBS under the State plan or a third-party medical resource agency.

§ 6100.483. Title of a residential building.

- This section does not address debt-free residential buildings. Providers use equity in real estate for critical loans and expansion.

§ 6100.485. Audits.

(b)&(c)(1) -(6) *Our comment:* This is already monitored by the IRS and does not need to be restated here.

§ 6100.486. Bidding.

(b) The cost must be the price made by a prudent buyer.

- Too nebulous to be a regulation and not needed if requiring a bidding process.

§ 6100.571. Fee schedule rates.

(a) Fee schedule rates will be established by the Department using a market-based approach based on current data and independent data sources.
- Define "market-based approach", rates should be based on a reputable consumer price index. The process needs to be transparent for individuals, families, and providers.

(b) The Department will refresh adjust rates based on a reputable consumer price index ~~the market-based data used in subsection (a)~~ to establish fee schedule rates at least yearly~~.~~

- To ensure that future rate increases directly benefit individuals, we recommend ODP setting reasonable limits on administrative costs.

§ 6100.642. Assignment of rate.

(b)&(c) *Our comment:* Using area adjusted average rates to set the eligible rates for new residential habilitation programs could disincentivize providers from serving higher need individuals.

§ 6100.741. Sanctions., § 6100.742. Array of sanctions.

- "Sanctions" should be changed to "remediation" or "corrective action."

§ 6100.802. Agency with choice.

- While some regulatory relief is available to AWC providers, this chapter is more relevant to licensed providers and is counter-productive to supporting family-based models as noted earlier. We recommend moving AWC from 6100 regulations as noted in previous comments. A separate agreement for AWC administrative providers should be developed. If the Department elects to keep the AWC providers in this chapter, then other sections should also be excluded. Since managing employers work with the individual and are considered volunteers, providing 12 hours of training for managing employees is very challenging. There are significant costs to oversee and train the managing employers.

- Are managing employers now required to have background checks? For a managing employer of a minor, are they not able to begin their duties as a managing employer until his/her background checks are completed?

- Section 6100.183 should not apply since it is for a residential facility.

- If AWC remains in Chapter 6100 remove 6100.48, 6100.52, 6100.55, 6100.141-144, 6100.405 and 6100.183 at a minimum.

§ 6100.803. Support coordination, targeted support management and base-funded support coordination.

(e)(2) *Our comment:* This appears to inappropriately limit reporting incidences, alleged incidences and suspected incidences to what those incidences the coordinator, manager, or supervisor observes directly.

§ 6100.806. Vendor goods and services.

(c) Payment for vendor goods and services will only be made after a good or service is delivered.

- There needs to be an exception to this for families who must make a down payment or pay fees prior to service delivery; for example, a camp and the family may not have the funds available to prepay.

- Who will confirm that the respite camps are fulfilling the requirements for training, individual rights, PSP, positive interventions, incident management, and medication? Some respite camps are seasonal, so how could they meet every three months?

- Most vendors do not access the individual's PSP so how would they be able to complete the appropriate support delivery documentation?

- A vendor of a home adaptation, specialized supplies, and vehicle adaptation should not have 12 hours of training per year. If vendors provide services for multiple providers, how would providers know which vendors were trained and not trained?

- If vendor services remain in Chapter 6100 remove all training sections and 6100.48, 6100.52, 6100.55, 6100.141-144, 6100.405 and 6100.183 at a minimum.

The Arc strongly supports the recommended regulation language below from the Imagine Different coalition.

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

(c) 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.

(d) 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. 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." ***Section 6100.223(11) shall not be applied to children.***

CHAPTER 6500. ~~LIFE SHARING HOMES~~ [FAMILY LIVING] LIFESHARING HOMES

§ 6500.3. Applicability.

(f)(1) *Our comment:* This Appears to exempt private homes of relatives providing care. What protections will exist for those living with relatives who are paid to provide supports in their private home?

Conclusion

The Arc of Pennsylvania recognizes these proposed regulations took a monumental effort from the Office of Developmental Programs, and we appreciate the dedication evident in them to ensuring the well-being of Pennsylvanians with disabilities and their families. Thank you again for the opportunity to comment on the proposed

regulations; the perspective of advocacy and provider organizations is critical to ensuring people with intellectual and developmental disabilities in Pennsylvania can access agile, person-centered services. If you have any questions, please feel free to contact me directly at mcronin@thearcpa.org or 717-234-2621.

Sincerely,

Maureen Cronin
Executive Director
The Arc of Pennsylvania

cc Nancy Thaler, Deputy Secretary for the Office of Developmental Programs