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14-540 307

Kroh, Karen

From: Mochon, Julie
Sent: Wednesday, December 21, 2016 8:56 AM
To: Kroh, Karen
Subject: FW: Regulation No. 14-540
Attachments: Emmaus Comments on Ch 6100 Program Only-1.docx; Comments Cover Letter.docx

From: Kelly Stillwell [mailto:kstillwell@emmauspgh.org]
Sent: Tuesday, December 20, 2016 7:51 PM
To: Mochon, Julie
Subject: Regulation No. 14-540

Hello Ms. Mochon,
Please see my attached letter and comments regarding the Chapter 6100. Thank you!
Kelly

Kelly O. Stillwell
Director of I/DD Services
Emmaus Community of Pittsburgh
412-381-0277 Ext. 213

RECEIVED
DEC 19 2016
Independent Regulatory
Review Commission

December 20, 2016

Ms. Julie Mochon

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

Dear Ms. Mochon:

Thank you for the opportunity to submit comments on the proposed Chapter 6100 regulations. I have been working in the field for more than 20 years, and I am enthusiastic to provide input in this legacy.

The Emmaus Community of Pittsburgh is dedicated to providing high quality services to people with Intellectual Disability and Autism, and we look forward to the continued success of the PA Dept. of Human Services ODP!

Sincerely,

Kelly O. Stillwell

Director of I/DD Services

Emmaus Community of Pittsburgh

412-381-0277, Ext. 213

Emmaus-Comments Template
Chapter 6100

Citation: **6100.1. Purpose (a)**

Discussion: **The wording is confusing**

Recommendation:
This chapter governs the provision of and payment for Home and Community Based Services (HCBS) and base-funded services to individuals with an Intellectual Developmental Disability (IDD) or autism.

Citation: **6100.2. Applicability**

Discussion: **Licensing and the regulations put forth here sometimes conflict.**

Recommendation: Add "In the event of a conflict between the regulations set out in this Chapter and related but separate licensing regulations, the licensing regulations apply and supersede this Chapter."

Citation: **6100.3. Definitions**

Discussion: Please discontinue using the word "facility" throughout the proposed Rulemaking. This implies that people are living in an institution. We are providing "homes" for people with IDD and Autism.

Recommendation:
The Home and Community based home hall monitor an individual's risk, etc. etc.

Citation: **6100.42. Monitoring compliance**

Discussion: **Having multiple AEs complete monitoring is time consuming and costly and unnecessary. The AE is the consult for the State, so what difference does it make which AE conducts the Monitoring? Re: corrective action plan: it does not seem reasonable to be required to have a CAP for an "alleged violation" if the allegation turns out to be FALSE or Inconclusive.**

Recommendation: Specify that only ONE AE should be allowed / required to complete provider monitoring

Do not require CAPs for false allegations or Inconclusive.

Citation: **6100.43. Regulatory waiver**

Discussion: When a waiver is requested it is very rarely due to a temporary condition. It is almost always due to a permanent need the individual has. An annual request is a costly and redundant exercise.

Recommendation: Allow waivers to renew automatically UNLESS there is a life changing event that warrants it's revocation.

Citation: **6100.44. Innovation project**

Discussion: **Sounds interesting!**

Recommendation:

Citation: **6100.45. Quality management**

Discussion: **While quality management is important, the new chapter poses several nearly impossible requirements such as "individual and family satisfaction surveys *and informal comments by individuals, families and others"* or "analyzing the successful learning and application of training in relation to established core competencies." (VERY general and VERY vague and VERY cumbersome) Providers have only had 3 years of experience under the newly required QM under Chapter 51. The extent of changes is not necessary.**

Recommendation: A provider will implement an evidenced based, quality improvement strategy that includes continuous improvement process, monitoring, remediation, measurement performance and experience of care.
(a) When developing a quality improvement strategy, a provider must take into account the following:
(1) The provider's performance data and available reports in Department's information reporting system.
(2) The results from provider monitoring and SCO monitoring.
(3) The results of licensing and provider monitoring.
(4) Incident management data, including data on incident target(s), repeated or serious incidents, root cause analyses, and quarterly review of incidents.
(5) Results of satisfaction surveys and reviews of grievances.
(b) The provider will include the following tasks as part of its quality improvement strategy:
(1) Goals that measure individual outcomes, experience, and quality of care associated with the receipt of HCBS and related to the implementation of PSP. Absent criteria established by the U.S. Health and Human Services Secretary, providers will establish goals based on identified need within their programs.
(2) Target objectives that support each identified goal.
(3) Performance measures the provider will use to evaluate progress.
(4) The person responsible for the quality improvement strategy and structure supporting this implementation.
(5) Actions to be taken to meet the target objectives.
(e) A provider must review progress on the quality improvement strategy and update at least every 2 years.
(f) A provider will maintain a written copy of the quality improvement strategy to be available for the Department to review as part of provider monitoring.
(g) This section does not apply to an SSW provider and to a provider of HCBS in the Adult Autism Waiver."

Citation: 6100.46. Protective services

Discussion: In HCSIS/EIM it is asked if Protective Services were notified, when you still have 24 hours to notify Protective Services and/or enter the Incident into HCSIS/EIM. If it is suspected or alleged, why do we have to notify the Department?? If it is founded to be a false accusation or inconclusive then why should we immediately report it to the Protective services. Can't time be provided to investigate and then give our (the providers) findings?

Recommendation: Clarify the provider shall *Immediately* report the abuse, suspected abuse or alleged abuse to the following:

Citation: 6100.50. Communication

Discussion: It is sometimes difficult, if not impossible, to truly ascertain whether or not, or how much an individual understands.

Recommendation: add language such as "Written, oral and other forms of communication with the individual, and persons designated by the individual, shall occur in a language and means of communication *as best and to the extent understood* by the individual or a person designated by the individual.

Citation: 6100.51. Grievances

Discussion: An employer, cannot and will not tolerate retaliation. However, and employer cannot "assure" that another employee or co-worker or family member or individual will not act in a retaliatory way. The types of grievances should be spelled out (addressed here and in the waiver).

Recommendation: Consider rewording to "will not tolerate...."
Re: 6100.51 (i) add "if known" (because the initiator might not be known)

Re: 6100.51 (i) – add wording to prohibit the contents of written notice from violating anyone's confidentiality. (those who file complaints sometimes demand or expect more information than they are entitled to)

The department must address / spell out the types of grievances that this waiver intends. It is not uncommon across the state, for family members to refuse to accept services from staff person if they do not like the color of their skin or because of their sexual orientation. Family members must understand that by accepting a Medicaid waiver for their loved one, they must also adhere to federal law prohibiting discrimination.

Citation: 6100.52. Rights team

Discussion: Providers work very hard to honor and protect individuals' rights. When someone's rights are violated, an incident is reported and investigated. This new requirement cannot be implemented as written for the following reasons: The code states that each provider is "required to have a rights team" however all of the subsequent requirements make it clear that *each individual* has a rights team based on each incident. In fact the individual is ON the team. Thus a provider could potentially have dozens of rights teams – one for each individual who has a rights (or alleged rights or suspected rights) violation. To require the team to (iii) "discover and resolve the reason for an individual's behavior" is antithetical to an understanding of

human behavior (an individual's behavior can be supported, understood, addressed, etc) but NOT RESOLVED. Additionally, with rights violations – a provider is most concerned with the *behavior* of the "target" – the person who violated someone else's rights. No need to "blame the victim" – as if something in their behavior caused an incident or a rights violation. Meeting quarterly with the individual for something that happened in the past is not productive. Making the team a majority of persons who do not provide direct services is not helpful precisely *because* they are not involved in the day to day care of the individual and the dynamics between the individual and other staff or other individuals. Often times they do not understand the individuals' needs or even how to communicate with the person. Following an Incident, the team meets regardless of the outcome usually, therefore a Rights team is redundant and time consuming!

Recommendation: Delete this section. There is no need to add a separate "Rights Team." In associated licensing regulations, a long-standing and well-stablished process exists for the oversight and appropriate management for the use of any restrictive procedures, including restraint. The regulations have already established the "Restrictive Procedures Committee" and restrictive procedures process which is tasked with the same basic functions of the newly created team. By replacing a currently existing and appropriately operation expectation, unnecessary costs are added to the system. It is entirely unclear why the creation of a new "rights team" is necessary or adds any value to the actual protection of individuals' rights, but rather only would add cost and administration burden. Individuals who are not satisfied with the follow up or corrective action plan have recourse to filing a complaint or grievance.

Citation: 6100.53. Conflict of interest

Discussion: Having an individual or a friend or family member of an individual serving on the governing board is a CONFLICT OF INTEREST by definition and shouldn't be permitted. They could be on another governing board of a different agency, but not the one that is directly providing services to the individual or family member.

Recommendation: Take out (c) of 6100.53

Citation: **6100.81. HCBS provider requirements**

Discussion: **The regulation wording under provider requirements should more accurately match *the actual* requirement for provider enrollment (for example – a license from the Dept. of Health" is mentioned in 6100.81 (c) – but is NOT in fact required for most facilities. This is VERY important, because provider enrollment has historically been extremely slow and is often held up because providers miss one or two documents – that were NOT listed correctly / clearly in the published directions. This then caused LONG delays for providers and worse – for individuals waiting to receive services.**

Recommendation: Include wording that matches the actual provider requirements:
A provider enrollment application, on a form specified by the Department.
A medical assistance provider agreement, on a form specified by the Department.
A home and community-based waiver provider agreement, on a form specified by the Department.
Verification of compliance with § 6100.81(2) (relating to pre-enrollment provider qualifications).
Verification of compliance with § 6100.476 (related to criminal history background checks).
Documents required in accordance with the Patient Protection and Affordable Care Act (Pub. L. No. 111-148).
Verification of successful completion of the Department's pre-enrollment provider training as specified in § 6100.142 (related to pre-enrollment training).
Monitoring documentation
Copies of current licenses, if applicable, as specified in § 6100.81(2) (relating to provider qualifications).
Verification of compliance with § 6100.46 (related to criminal history background checks).
Prior to applying for participation in the HCBS program, the applicant shall complete the Department's pre-enrollment provider training.

Additionally: 6100.81 (c) 1 & 2 seem to contradictory or confusing. Please clarify.

Citation: **6100.82. HCBS documentation**

Discussion:

Recommendation:

Citation: **6100.141. Annual training plan**

Discussion:
Because of the unique needs of the many individuals served by providers – not ALL positions will require the same courses (6100.141 d(2), Some DSPs need a lot of training on aging issues, others on medical issues, and other on behavioral health issues – to name a few. There needs to be some flexibility. This requirement seems to be asking that every staff member has an annual training plan – that must – at a minimum cover certain topics.

Recommendation: Re; 6100.141(c) Please list the core competencies so that system wide expectations are clear. Please delete the Annual Training Plan. Every staff person is required to have 24 hours of training per year and this is feasible given the MANY demands upon staff. Program Specialists usually have MANY hours beyond the 24. If you are going to maintain the Annual Training Plan, you must raise wages for staff. No one is going to want to continue to work in this field on the current wages!

Citation: **6100.142. Orientation program**

Discussion: **When a provider hires a consultant, it is usually because the consultant possesses some professional expertise that the provider does not have. Adding a training / orientation requirement for consultants will add hours and cost to consulting agreement. Additionally, the topics identified (abuse, rights, incident reporting and job related skills) are often (though not always) way outside of a consultant's responsibility. The provider is still ultimately left with the responsibility of reporting, addressing and following up on all such matters.**

Recommendation: Consultants should not be required to receive such detailed orientation because 1. They are competent professionals 2) there is too much time and cost involved – and sometimes individuals and agencies need help quickly and 3) Consultants who are used by more than one agency – by this definition would need to be "orientated" by every agency they work for.

Recommend *the Department* develop and administer a training for consultants so that providers are not re-inventing the wheel – all mandated topics are statewide. This would mean NO COST to the providers.

Recommend that for all non-DSP / program staff – orientation and training focus on "Everyday Lives" – a code of ethics, and the "big picture" rather than on specific policies and procedures which they most likely will never have to act on.

Citation: **6100.143. Annual training**

Discussion: **As written, the regulations are confusing. It would make more sense to address orientation first, and then move on the annual training plan and annual training. It is "splitting hairs" to make these separate – since there is so much overlap.**

Specifying that 8 of 12 hours must be on certain, listed topics is unnecessary, because the items that MUST be covered will take at LEAST 12 hours if done correctly.

Additionally, while the topics listed in the waiver are important and necessary – and presumably the rates will be built to meet the 12 & 24 hour requirement, providers are still required to cover many training topics that are not listed such as: medication administration (16 -24 hours alone!), fraud waste and abuse prevention, compliance issues, handling grievances and complaints, proper documentation of service delivery, safe vehicle use, safeguarding client resources, quality management, professionalism, interacting with family members, ODP monitoring requirements, emergency medical treatment, fire safety, first aid, CPR and more.

The Department must understand that providers are required – whether mandated by regulation – or by best practice – or by agency requirement, to provider extensive training that goes way beyond 24 hours of narrowly focused requirement. And must set rates accordingly. Compliance with bare minimum standards will not ensure system wide quality.

Recommendation: AWC and OHCDS should be removed from the regulations and that Transportation Trip and Unlicensed home and community based providers be excluded from 6100.143 as written. This list of training is geared strictly towards licensed providers and impedes the promotion of family support models of service delivery. A prescribed number of hours for training will not support appropriate training specific for the individual and does not afford the opportunity for families/participants and the unlicensed providers and Transportation trip providers that support them with the type and frequency of training that is needed for the individual. When there are established mandates to hours versus individuality, the quality is a lost and the opportunity to supporting the values of ODP and everyday lives is lost. The current unit rates will not support the increase in training requirements. Optimally, AWC and OHCDS providers will be removed from 6100 regulations and unlicensed providers and transportation trip providers should have separate training requirements that do not include a specific number of hours. See comment under 6100.141.

Citation: **6100.144. Natural supports**

Discussion: **Better clarification of what or who is a Natural support should be defined.**

Recommendation: Better definition of Natural support is needed

Citation: **6100.181. Exercise of rights**

Discussion: **The language in 6100.181 (b) – is very vague: "shall be continually supported to exercise" his or her rights.**

Recommendation: Please specify exactly what is meant by "continually supported to exercise" rights. Explain how that is done, how it is documented, how it is proven or measured.

Citation: **6100.182. Rights of the individual**

Discussion: **Re: 6100.182 (b) If individuals have the right to speak freely, then they should also have the right to be free from allegations of and investigations of verbal abuse every time they say something that offensive to another individual.**

Recommendation: If this right is left as written, recommend adding that the individual will be held accountable for "speaking freely" if another individual, a staff person, a behavior specialist, or a consultant, feels that the speech is abusive or allegedly abusive.

Same recommendation for (e) – If a person makes a choice and "accepts" risks, then they should be free from accusations based on another individual's interpretation of that behavior. Currently - as related to incident management – providers are being required to enter incidents based on the values and perceptions of staff and other "outside" individuals and NOT on the individuals' words and actions or on the perceptions / understanding of the individual.

Recommend adding individuals have a right to be educated about the consequences for violating another's rights (perhaps addressed in 6100.183)

Citation: **6100.183. Additional rights of the individual in a residential facility**

Discussion: **It needs to be made clear that individuals have the right NOT to exercise all of their rights (ie: they have a right not to have a lock on their door if they so choose) In an everyday life – we all have the right to vote – but many choose not to. Some people choose not to have a mirror in their room and this is waived in the 6400 regulations. Why aren't other "rights" given the same choice? Additionally – many individuals have limited financial management abilities. A "right' to unrestricted access to telecommunications – could be interpreted as a right to a data / coverage plan that one cannot afford.**

Recommendation: Make clear that individuals rights can not conflict with regulation, with others' rights, or with documented health and safety information in the ISP. (ie: access to food at any time is clearly contraindicated for a person with Prader Willi)

Citation: **6100.184. Negotiation of choices**

Discussion: **The title here is mis-leading. The regulation is NOT referring to individuals' choices but rather to individuals' rights. Ie: the rights of one can not trump the rights of another.**

In group home / living situations – negotiation of choice is not an isolated "event" or a single conversation…but rather an ongoing dialogue and constant revision and compromise. Choice negotiation is extremely subjective – and based on many variables. No one procedure can be expected to resolve differences to everyone's satisfaction.

Recommendation: Since "rights" should be non-negotiable – the wording should reflect more accurately that which is intended by this regulation:

Suggest: Responsible exercising of rights

Citation: **6100.186. Role of family and friends**

Discussion: **Family and friends are by definition "natural supports." It is unreasonable to "regulate" that role. There is way too much variance in family roles / dynamics to mandate a provider role in "facilitating" and making "accommodations necessary."**

If all activity here is under the direction of the individual, then the provider has a very limited role to play – and again that role should NOT be regulated.

Recommendation: delete this section.

Citation: 6100.221. Development of the PSP

Discussion: An ISP is by definition a Person Centered Support Plan. The "plan" has undergone several title changes over the past 20 years, but the content remains virtually the same. Changing the language for the sake of a few updated / nuanced additions is un -called for. Additionally, it will require tremendous time and cost statewide at all levels. Have we changed the term IEP? Why do we need to change the terminology? Individual Support Plan is EXACTLY what is!

Recommendation: Continue to call the plan an ISP. Update content as desired.

Define what the "service implementation plan" is. (ie: is this a separate "plan" from the ISP?) Delete (b) all together.

Re: 6100.221 (f) – please define what constitutes a "current assessment"

Citation: 6100.222. The PSP process

Discussion: Please define how the individual "directs" the PSP process. Ie: What are they expected to do? How will they know what the PSP process is? What if they are not capable for directing the PSP process or they do not want to "direct" the process?

Recommendation: Rewording is needed:

6100.222 (b) (1) ….A PSP process does not invite and include individuals….An individual must identify and include individuals. Please describe extactly WHO is doing (b) 1-11.

Citation: 6100.223. Content of the PSP

Discussion: More information is needed: (11) are we setting our individuals up for failure? Not everyone is able or wants to be competitively employed or quite frankly integrated employment. Most people that I know like being with their peers.

Integration occurs usually in the community, actively when pursuing interests beyond work. When working, we are doing just that- working.

Recommendation: include information on behavioral supports needed. Delete (11) Not all individuals want to actively pursue competitive, integrated employment as a first priority, before other activities or supports are considered. This should be a Choice!

Re: (14) – consider adding this to 6100.184 – re: negotiation of rights / balanced w/ risk. Or refer to THIS reg under .184.

Citation: 6100.224. Implementation of the PSP

Discussion: Why are we changing the terminology from ISP to PSP? What is the point? And, if we change it, will it be changed in the 6400 Regulations? Will BHSL accept this change? Why should we change it and now confuse families and individuals? The individuals (and advocates) that I know, like the term ISP. Someone commented that PSP sounds like a drug and should not be associated with our individuals.

Recommendation: Maintain the ISP terminology

Citation: 6100.225. Support coordination and TSM

Discussion:

Recommendation: Change the word "assure" to "ensure"

Citation: 6100.226. Documentation of support delivery

Discussion: Clarify what is the Service Implementation Plan. In (f) a quarterly report is conducted by the provider and this is a 6400 Regulation. Will this qualify as the "complete review of the documentation"?

Recommendation: ODP should develop a statewide mandated form for use by all providers. This will greatly reduce "violations" due to variance among providers.
What is the Service Implementation Plan that is mentioned here? And clarify (f)- 3 month report?

Citation: **6100.261. Access to the community**

Discussion: **Somewhere in this regulation – the department needs to make it clear that – as in all everyday lives – individuals have to plan community outings "according to their means" (ie: they may want / desire / chose to have season tickets to the Pirates, but they can only afford to go to 3 games per year. Additionally, ODP must be willing to pay for the staff portion of "access to the community" because of the required role in facilitating it....and keeping people safe.**

Recommendation: Is it a choice for community involvement or isn't it? The premise of the 6100's seems to be based on the outdated and not well developed 51's. The 51's did not involve much input and are based on a fractured system. We have come very far and have made great strides. Our agency takes our individuals out into the community all the time. They go out more than I do! Providers should be given more money to take individuals out into the community so that staff can receive reimbursement for the activities. Some agencies do not provide reimbursement for activities, I've heard.

Citation: **6100.262. Employment**

Discussion: **Many of our individuals are living good long lives. Providers have been saying for years that folks should have the right to retire. There is no mention of people at or near retirement age.**

Recommendation: Add a provision for retirement – which is a valid component of an " Everyday life"

Citation: **6100.263. Education**

Discussion: **Higher education is very expensive.**

Recommendation: Please describe where the funding comes from for (1-4)

Citation: **6100.301. Individual choice**

Discussion: **Transitioning can be time consuming and expensive. Spending time with the new provider, providing staff for visits and transportation, etc.**

Recommendation: The Supports Coordinator should assist with transportation and visits, so as to remain neutral from old provider to new provider.

Citation: **6100.302. Transition to a new provider**

Discussion:

Recommendation: The supports coordinator should assist with transportation and visits, so as to remain neutral from old provider to new provider.

Citation: **6100.303. Reasons for a transfer or a change in a provider**

Discussion: **Discussion 6100.303:**
This section is defined too narrowly to be practicable to the point that it contradicts other portions of the chapter and are unable to execute the residency agreement. There are many circumstances such as program closure, safety of others, Megan's Law, eminent domain, court or other legal actions, eviction by a landlord of the provider, natural disasters, provider closure which may require transfer or change in spite of individuals' wishes. This list is not exhaustive – they regulation needs to allow for unforeseen occurrences.

What if exercising rights impinge on others, is that grounds for transfer? What if rights place the individual or others at risk? 6100.184(a) states, "An individual's rights shall be exercised so that another individual's rights are not violated."

Recommendation: Change (a) to read: A change in provider, against the individual's wishes will be made only in for serious reasons including:.....

Citation: **6100.304. Written notice**

Discussion: **There are 3 main parties involved in notice of a provider no longer being "willing or able" to provide a service: The SC, the individual / family, and the provider." There are many PSP team members who do not need to be informed of a change in one provider of one service. The Department and the AE will find out about**

the change when a critical revision or update is made. Since they have NO role in the decision about the change – they do not need notice of it.

Recommendation: delete (4) under 6100.304

Citation: 6100.305. Continuation of support

Discussion: There is a fundamental lack of understanding on ODPs part as to why it is sometimes impossible for a provider to continue providing services. The workforce is simply 1) not large enough (too many vacancies) or 2) qualified enough. When individuals have complicated medical or behavioral healthcare needs - a provider cannot simply pull staff out of thin air. Nor can a provider force staff to stay in a situation that they feel unsafe in or unqualified for. Even with additional funding – the enormous amount of pre-service training that is required makes replacing staff a very long process.

Recommendation:

Citation: 6100.306. Transition planning

Discussion:

Recommendation:

Citation: 6100.307. Transfer of records

Discussion: In order to maintain a person's health and well-being, additional time of sharing information is needed.

Recommendation: After learning of someone's choice to transition- The provider shall transfer a copy of the individual record to the new provider as soon as the individual requests the transfer.

Citation: 6100.342. PSP

Discussion: **Title "PSP' here will be confusing when also referenced in 6100.221 This section is only about a very narrow piece of the PSP namely "dangerous behavior"**

Recommendation: move this section to the PSP section

Strongly recommend finding a different term than "dangerous behavior" – which sounds predatory and has a tone that harkens back to the days of institutionalization ….and society's fears of people with IDD as "dangerous"

Consider: Risky behavior or potentially harmful behavior.

Citation: **6100.343. Prohibition of restraints**

Discussion: **Title can be misleading to appear that no restraints are allowed, ever**

Recommendation: Change title to "Prohibition of certain types of restraints."

Citation: **6100.401. Types of incidents and timelines for reporting**

Discussion: **Med errors should not need to be reported w/in 24 hours, but rather 72 hours as listed in**

Recommendation: re: individual to individual incidents: Require incidents to reported not just on the victim but on the "target" – There are many individuals who are the initiators of incidents – yet their behavior and support and corrective action plans and ongoing need for therapy – is NEVER captured or recorded.

Citation: **6100.402. Incident investigation**

Discussion: **The Department already has a mandated training for certified investigators – and they are trained on who to ask and what to consider. The entire process is comprehensive and thorough. There is no need for an additional "type" of investigation – ie: with a small "i". However – all incidents are indeed analyzed – both on an individual basis and quarterly – in relation to all other incidents.**

Recommendation: Move 6100.405 to 6100.403 – do not use the word "investigating" in any other way than when intended as "Certified Investigation"....this is more practical and useful to providers.

Citation: **6100.404. Final incident report**

Discussion: **Only the Certified Investigator can imply #2- the results of the incident investigation.**

Recommendation: (2) Add if applicable, the results of the incident investigation by the Certified Investigator

Citation: **6100.405. Incident analysis**

Discussion: the quality management team does this already but based on incidents that required a Certified Investigator. Incident analysis on each incident would create a hardship on already stretched thin staff. It is difficult to ascertain what is the "root cause of an incident" That is why there is an investigation, if applicable and a Corrective Action Plan in each incident.

Recommendation: Incident Analysis on Incidents requiring a Certified Investigator.

Citation: **6100.441. Request for and approval of changes**

Discussion: **There are many situations within which individuals would benefit from rapid placement. These situations include natural disasters, program closures, and removal from abuse. It is important that this chapter allow the department to develop an expedited capacity change process to accommodate individual's needs in their everyday lives.**

Recommendation:

Citation: **6100.442. Physical accessibility**

Discussion: **This item can create remarkable costs. The department needs to develop capacity to compensate providers for these costs in their rate-setting process.**

Recommendation:

Citation: **6100.443. Access to the bedroom and the home**

Discussion: **This proposed regulation, while presumably aimed at ensuring privacy, does NOT align in any way with an everyday life. Most citizens do not live in a house where they need a key to access their own bedroom. Additionally – in meeting individuals every day needs, staff may need to enter bedrooms many times per shift for many many non-emergency or non "life safety" reasons: helping to get dressed, assisting with bed making, collecting laundry or putting away clean clothes, helping to fix someone's hair, assisting with bed time routines or personal hygiene. Staff are always expected to treat the entering of individuals' rooms with respect – to ensure dignity and privacy – but to prohibit entry without "express permission" for each incidence of access – demonstrates a serious lack of understanding of the amount of personal assistance our staff are providing on a daily – hourly basis. Further, documenting or proving that "Required express permission of each incidence of access" was granted or denied will be impossible....and if not impossible – it makes a homelike environment seem very much like an institution. Staff who enter bedrooms on a regular basis are not strangers to the individuals. They are kind, caring and dedicated Direct Support Professionals who spend their hours, days, weeks and years building relationships with the individuals they support in a dignified manner.**

Recommendation: If an individual desires, chooses or requests that a lock be put on their bedroom door, then a provider will ensure that it happens.

Re: (e) Please specify who decides who is "authorized" – by name? by title? By position? Recommend language: The rights of the individual to privacy in his/her bedroom should be respected in accordance with sections 6100.181-183, with consideration for the needs of the health, safety, and welfare of the individual as determined in the PSP, or as needed in an unforeseen or emergency circumstance.

Recommend – addressing individual complaints or accusations of violation of privacy – as needed.

Recommend working to reflect language from the Community Rule: Each individual has privacy in their individual sleeping or living unit: Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors.

Citation: **6100.444. Lease or ownership**

Discussion: **It is necessary under the Community Rule that individuals have a legally enforceable document that offers the same responsibilities and protections from eviction as our prevailing law. To that point, 6100.444(a) is clear and direct. 6100.444(b) while describing reasonable limits, inadvertently refers to providers as "landlords" and to individuals as "tenants" and their units as "leased space". The rights conferred under the rule and as cited in 6100.444(a) do not make providers landlords. Having the same protections as provided by law does not make individuals tenants nor their spaces "leased". This language distinction is important in that we need to preserve the American Disability Act's protection of community residences as homes rather than businesses which can be excluded from residentially zoned areas. This distinction will also be crucial if/when the state develops guiding language or uniform formatting for the residency or room and board agreements in the future.**

Additionally – it has already been made clear in regulation 6100.303 regarding the conditions that are grounds for transferring (ie: discharging) an individual.

Recommendation: Remove reference to the Landlord and Tenant Act of 1951. It is not nuanced enough for the actual purpose of an enforceable agreement between a provider and an individual with IDD.

Citation: **6100.445. Integration**

Discussion:

Recommendation:

Citation: **6100.446. Facility characteristics relating to size of facility**

Discussion: **It is not clear whether or not this new regulation is legal or not. The use of a maximum number seems – by the Department's own admission – completely arbitrary, and should therefore be omitted. Capping a number of participants working or living near one another seems contrary to ADA and Everyday Lives. The Community Rule does not specify an absolute cap on program size and so neither should Pennsylvania.**

Recommendation: Do no place an arbitrary maximum number of participants into the regulations.

Citation: **6100.447. Facility characteristics relating to location of facility**

Discussion: **6100.447 (a) 1 & 2 & 5 are redundant**

It seems that someone with compromised health, or aging needs, or a chronic behavioral or physical healthcare need –could benefit from living in "close proximity" to a hospital. No need to disallow it. Lots of people *without* disabilities live in close proximity to hospitals and nursing facilities – people with IDD should be "allowed" to too. Otherwise – expressly define "close proximity" as it is extremely vague – and could mean one thing in an urban area and another thing in a rural area.

The system has been moving away from institutionalization and segregated living for decades. As more and more programs and services open up IN the COMMUNITY – there will be closer proximity to one another. It seems that this regulation is trying to tix something that is NOT broken. Unless the Department can provide evidence that people are being served in super-congregate settings, or show some evidence based research / data that shows the trend is heading that way, then COMMUNITY providers should have more flexibility in where they develop COMMUNITY based services.

Additionally – regarding the waiver renewal and the addition of people with Autism, the Department should be aware of a movement TOWARDS congregate living – in an effort to foster acceptance and share resources (see http://www.ahdcp.org/)

The regulations should be careful not to single out people with IDD as SO DIFFERENT than everyone else – that this set of regulations could never apply to another population.....especially while purporting to reflect the values of Everyday Lives.

Recommendation: Consider how discriminatory and limiting this regulation is.

Citation: **6100.461. Self-administration**

Discussion:

Recommendation: Add Epinephrine injections for insect bites or other allergies

Citation: **6100.462. Medication administration**

Discussion: **Discussion: Medication Administration**
There are two extremely important issues concerning the proposed new regulations pertaining to medication administration. These need to be addressed to prevent unintended negative consequences.

1. Codifying content that requires modifications over time into regulations will lock a crucial component of service provision into temporal practices which will become obsolete as new information, prevailing practices and technology emerge. Duplicating content which is as detail-specific as the proposed five-and-a-half pages of regulation across 5 sets of regulations when the state already has an externally -accepted training module invites discrepancy between the regulations and the training manual and prohibits the training module from staying current as new information, prevailing practices and technology emerge.

2. Requiring 6500 LifeSharing providers to complete and adhere to ODP's Medication Administration Module is a new and counterproductive requirement which is in direct contract to Everyday Lives principals and the Department's stated intent to develop more integrated and natural life opportunities for individuals.

As a ready example of the problem with codifying material which requires change over time, an area has been identified in which the proposed regulations are at odds with prevailing practices as detailed by Title 49 of the State Nursing Board. 49 PA. CODE CH. 21 explicitly provides for Licensed Practical Nurses to accept oral orders for administering medication. The proposed 6100.465 provision only allows this practice for Registered Nurses.

This discrepancy is instructive both to the specific issue regarding LPN's and to the process issue of codifying Nursing Practices content which changes from time to time according to authorities outside of the Department. It is noted that the provider system needs LPN's to be able to do all that state law provides for them to do. In the second case, we need regulations which do not lock providers to standards which may soon become obsolete due to new and emerging best practices and advances. A second example of the problem with trying to maintain this content in multiple places is that there are already discrepancies between the proposed 6100's and the Department's Approved Medication Administration Training. The training's required checklist for medication self-administration has discrepancies with the proposed regulation. There is also a notable practice discrepancy regarding pre-pouring of medications. We should avoid such confusion by maintaining this content in just one place, namely the Medication Administration Training module and not regulations.

Recommendation: Keep the current medication policies and procedures in place.
The application of Epinephrine injections should NOT be included in the Medication Administration. As with any parent that has a child with food allergies, staff can read the instructions and administer Epinephrine injections as necessary. Do Not make this part of the ODP Medication Administration training. Anyone that can read, as our staff can, may implement an Epinephrine. This could be life threatening and the medication training is very timely and expensive. If someone is not able to pass medications yet, they would be unable to administer an Epinephrine injection.

Do NOT cover 6500s in this regulation.

Citation: **6100.463. Storage and disposal of medications**

Discussion: **If it isn't broken, don't fix it. It is unclear why there are so many changes recommended under the medication section. It is also unclear as to how these changes will, if at all, improve or enhance quality.**

Recommendation: Keep the current medication policies and procedures in place.

Citation: **6100.464. Labeling of medications**

Discussion: **If it isn't broken, don't fix it. It is unclear why there are so many changes recommended under the medication section. It is also unclear as to how these changes will, if at all, improve or enhance quality.**

Recommendation: Keep the current medication policies and procedures in place.

Citation: **6100.465. Prescription medications**

Discussion: **If it isn't broken, don't fix it. It is unclear why there are so many changes recommended under the medication section. It is also unclear as to how these changes will, if at all, improve or enhance quality.**
(d) Please clarify. So, if Tylenol is prescribed to 3 individuals in the same home, they are not permitted to share the same Tylenol container?

Recommendation: Keep the current medication policies and procedures in place.

Citation: **6100.466. Medication records**

Discussion: **If it isn't broken, don't fix it. It is unclear why there are so many changes recommended under the medication section. It is also unclear as to how these changes will, if at all, improve or enhance quality. © if the individual refuses the prescriber should be notified? Often if it is a designated behavior or typical for the person, it is included into their ISP and/or in their Behavior Plan if deemed necessary by the team.**

Recommendation: Keep the current medication policies and procedures in place.

Citation: **6100.467. Medical errors**

Discussion: **If it isn't broken, don't fix it. It is unclear why there are so many changes recommended under the medication section. It is also unclear as to how these changes will, if at all, improve or enhance quality.**
I am a Certified Medication Administration Trainer and I can say that the new training, as the old, is still timely and difficult. Many people do not pass the first time. And, can't take it again for 6 months if they fail the second time. This is a labor intensive training and skill. Medication errors occur at times, because we are not Nurses and we are doing ALL the other requirements, like integrating people into the community, working on outcomes and goals, quarterly reports, cooking dinner, transporting people, helping people to socialize, implementing behavior plans, assisting with evening hygiene routines, etc. There are many medications on most occasions. I wonder how many medication errors occur in the hospitals? And, Nurses make a lot more money than our staff.
Medication errors do unfortunately occur, but please delete (b) and (c)-the prescriber's response shall be kept in the individual's record. Medication Errors are reportable in HCSIS/EIM within 72 hours. Usually, a provider will call the PCP and/or Pharmacy following a medication error, but not the actual prescriber. However, calling the prescriber would add undue stress and timeliness to the incident. It would not provide an added benefit to the individual. The health and safety of the individual was already addressed at the time of the error. Usually the staff is already upset regarding the error, they are observing for side effects, and remediation follows by a Supervisor or Certified Medication Trainer for the Incident in HCSIS/EIM.

Recommendation: Keep the current medication policies and procedures in place.
Delete (b) and (c)- the prescriber's response shall be kept in the indivdual's record.

Citation: **6100.468. Adverse reaction**

Discussion: **If it isn't broken, don't fix it. It is unclear why there are so many changes recommended under the medication section. It is also unclear as to how these changes will, if at all, improve or enhance quality.**

Recommendation: Keep the current medication policies and procedures in place.

Citation: **6100.469. Medication administration training**

Discussion: **If it isn't broken, don't fix it. It is unclear why there are so many changes recommended under the medication section. It is also unclear as to how these changes will, if at all, improve or enhance quality.**

Recommendation: Keep the current medication policies and procedures in place. Remove Epinephrine training. Anyone that is able to read can administer an Epinephrine injection. It will be a safety concern if staff present that are NOT medication trained are NOT able to administer an Epinephrine injection when needed. At times, agencies utilize staff that are not med trained in homes where the person is self-medicating or they partner with other houses so that a staff that is med trained can administer the medications at a prescribed time. Do not include Epinephrine injections into the medication administration training. Providers can train staff on Epinephrine injections on their own. It is literally a 10 minute training that can be done appropriately, separate from the Medication Administration Training.

Citation: **6100.470. Exception for family members**

Discussion: **Family members should however, be expected to administer medications in the proper way (correct dose, route, time/s, etc.) failure to do so sometimes both compromises the individuals' health and also puts the provider – which knowledge of such mistakes (or intentional decision to not follow doctor's orders), at risk. Elderly parents often forget…or sometimes have different ideas of what their child / relative actually needs. Or might believe in cutting the pills in half to make them last longer (like they do for themselves). Or they have been given**

"discretion" by the doctor to "up" or "down" the dose according to observations…etc. Discretion that our staff do not have. This is a difficult situation for providers. Some clarification would be helpful here.

Recommendation: Why are family members not expected to follow appropriate medication administration?

Citation: 6100.571 Fee schedule rates.

Discussion: In order for staff to remain at the high quality that we are requesting given all of these standards, and other requirements, ODP will need to address the cost of living increase. What does the word "refresh" mean? Please clarify.

Staff that are providing services are good people with good intentions. They need to be reimbursed for ALL of this hard work!