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Emmaus Community of Pittsburgh

A Community that Serves Persons with Intellectual Disabilities and Autism and Promotes Public Awareness of Their Needs

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

REFERENCE REG. NO. 14-540

December 16, 2016

Dear Ms. Mochon,

Please accept my enclosed comments on the proposed Chapter 6100 regulations. I currently serve as the Director of Development for the Emmaus Community of Pittsburgh. Additionally, I serve on the Quality Management Committee and am a Certified Investigator for the organization. I have been an employee of the Emmaus Community for more than 13 years and have previously held the roles of Residential Advisor and Direct Support Professional.

Having served in a variety of roles, I am very familiar with the current regulations and the needs of individuals receiving Home and Community-Based Services. As a sibling of an individual with an intellectual disability, I also believe in holding providers to the highest standards of quality. I am proud of the dedication demonstrated by our team at Emmaus, and I look forward to continuing to partner with the Office of Developmental Programs to further our mission and improve people's lives.

I know that in soliciting the feedback of those who are directly implementing these services, you will be able to ensure that the Chapter 6100 regulations are truly meeting the needs and protecting the rights of individuals with intellectual disabilities in our State. Thank you for the opportunity to contribute.

Sincerely,

Tiffany Merriman-Preston

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Director of Development

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Comments Template
Chapter 6100

Citation: **6100.42. Monitoring compliance**

Discussion: **Current wording requires a corrective action plan for a "violation or alleged violation." If an allegation of a violation is determined to be unfounded, a corrective action plan is not necessary, efficient, or beneficial to the individuals receiving services.**

Recommendation: Remove "or alleged violation" from current wording.

Citation: **6100.43. Regulatory waiver**

Discussion: **A waiver request may be in response to a permanent change in an individual's needs. In this case, an expiration date requiring a regular renewal request is costly and redundant for the provider.**

Recommendation: Allow waiver requests to renew automatically unless specific circumstances deem an expiration date to be necessary.

Citation: **6100.45. Quality management**

Discussion: **Quality management needs to focus on measurable, outcomes-based data. Current language includes several overly subjective data points, including "informal comments" and "an analysis of the successful learning and application of training." Providers need the flexibility to design and measure outcomes according to individual program needs and available data.**

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: 6100.52. Rights team

Discussion: As currently written, it is very difficult to understand how exactly the rights team is intended to operate and what function it serves that is not duplicated elsewhere. The language seems to suggest that each provider should assemble a rights team, when in fact, the requirements would demand that each individual have their own rights time. Accordingly, it's unclear how an "MH and ID program rights time" could be substituted.

The rights team is tasked with reviewing each incident, but the certified investigator is already tasked with this, and individuals, family members, and independent supports coordinators are already notified of any alleged rights violations and participate in implementing corrective action plans.

The suggestion that a rights team has the ability to "discover and resolve the reason for an individual's behavior" is an unreasonable expectation.

The suggested make-up of a rights team is nearly identical to the current make-up of an ISP team, soon to be a PSP team, so this work is duplicative. Additionally, it is unreasonable to expect the already over-taxed managing entity to be represented on every rights team, when every individual will require a rights team, and the team will be required to meet every three months.

The requirement that a rights team meet every three months, minimally, is very unclear. Is it regardless of whether a rights violation has been alleged? If a rights violation has been alleged, does the team meet indefinitely, for the rest of the individual's life?

Recommendation: Delete this requirement. The section is not clear enough for a provider to ensure compliance, and the purpose of the rights team is duplicated in various other regulations.

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 who receive orientation from their employers for their specialty of work 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: 6100.144. Natural supports

Discussion: Natural supports need to be more specifically defined. As written, any volunteer would qualify as a natural support.

Recommendation: Define natural supports more specifically.

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: 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: 6100.221. Development of the PSP

Discussion: The name change of the ISP does not represent a change in approach, as the plan is already structured around person-centeredness and everyday lives. The change is costly and inefficient

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

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:**

Recommendation: include information on behavioral supports needed.

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

Citation: **6100.226. Documentation of support delivery**

Discussion:

Recommendation: ODP should develop a statewide mandated form for use by all providers. This will greatly reduce "violations" due to variance among providers.

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:

Citation: **6100.263. Education**

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

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

Citation: 6100.443. Access to the bedroom and the home

Discussion: While all individuals have a right to request a key lock on their bedroom door, requiring them to exercise that right is enforcing a more institutional environment, rather than an every day life.

Recommendation: Re-word this regulation to express that individuals have a right to request key entry to their bedroom doors, if desired.

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: 6100.446. 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 regs. Recognize the great cost associated with the rule, which is not currently funded and could result in program closures if enforced without rate increases.

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

Discussion: **"Close proximately" is not specifically defined. Additionally, in an urban setting, many residential neighborhoods include houses in close proximity to many of these institutions. To regulate that a residential home for people with intellectual disabilities cannot be located in close proximity to a hospital or a completely unrelated health or human service organization is to greatly diminish the options of individuals who choose to live in an urban setting or a neighborhood that includes this diversity of businesses.**

Recommendation: Consider how this regulation places undue restrictions on individuals with intellectual disabilities seeking to live in the community.

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. **Do NOT cover 6500s in this regulation.**

Citation: **6100.648. Donations**

Discussion: **Currently, allowable costs are not fully reimbursed. Putting limitation on donations puts providers in an impossible position and impacts the quality of the services provided**

Recommendation: Remove regulations pertaining to donations.