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From: SSpreat@woods.org
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To: IRRC
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Attachments: 6100 Regulations comments 110716.docx; 6400 regulations comments 110716.docx

Dear colleagues,

I am offering comment on regulations proposed by the Department of Human Services. Specifically, I refer to IRRC# 3160, 55 Pa Code Chapters 6100 and 6400. I have attached my comments to this email. Thank you for allowing this participation,

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President / Woods Programs
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6100 Regulations

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- **6100.1 – Purpose** – to be clear, these regs pertain only to HCBS funding and base funding of PA residents. They do not appear to pertain to individuals from other states or individuals who are funded by any entity other than HCBS or county based funding. If I understand correctly, nothing in this set of regulations impacts on persons funded by schools, insurance companies, managed care entities, child welfare systems, or private funding.
- **6100.2.c – Applicability** - According to this standard, the chapter applies to programs that are funded “exclusively” by base funding or the HCBS system. Specifically excluded is out of state funding and private funding.
 - Recommendation: add school funding, insurance funding, managed care funding, and child welfare funding to the list of exclusions. Define “exclusively” to mean that all funding for an included program comes from base funding, and that if base funding is only part of the mix of payers, the program is excluded. Note that “program” is not defined.
 - Question: how will you apply these regulations for programs that have a mix of included and excluded funding? I seem to recall that the 4300 regulations do specifically address this possibility.
- **6100.42.g – Monitoring compliance** – This regulation gives the department the authority to direct the operation of a private business through directive corrective action plans. I can’t see how this would be legal. I understand that the department could elect to not do business with a private business that doesn’t develop a satisfactory correction plan, but they should never intrude on the operation of a business. Suppose their directed operations result in a negative outcome. Who is responsible? If the company goes bankrupt, is the commonwealth in some way responsible?
 - Recommendation – have the legal department opine on the legality of this regulation. It would seem that the Commonwealth could elect to not do business with an agency that submits a corrective action plan not to the Commonwealth’s liking, but if the Commonwealth directs the corrective action plan, one would certainly think that the Commonwealth now assumes some of the liability for the program.
- **6100.44 – Innovation project** – Per regulation b.2, the submitter of an innovation proposal shall describe the positive impact of the innovation project. It would seem that by definition, the outcomes for an innovation project are unknown. If they were known, it wouldn’t be an innovation project. The submitter could state the hypothesis that is being tested by the innovation project, but a hypothesis is always stated in the null form. Most professional ethics standards forbid the promise of outcomes, and I would think that standard should be applied here as well. Providers should not be encouraged to promise outcome promises in return for approval of an innovation project.
 - Recommendation – remove the requirement for description of the positive impact of innovation projects. Its inclusion is just an empty promise. Same goes for the ODP Deputy Secretary’s review – it shouldn’t be reviewed on the promised outcome.
- **6100.45 – Quality Management** – I wonder if anyone realizes what a major task it will be to analyze PSP outcomes? We’re talking apples and sailboats here. How in the world does one compare a shoe typing goal with a goal to get a job? Goal attainment scaling is one option, but

the shortcomings of that approach are widely reported in the literature. Percentage of goals attained draws similar problems. Keep in mind that program evaluation is a profession, and that most agencies lack professionals with expertise in program evaluation.

- Recommendation – Perhaps the commonwealth should hire Center for Outcome Analysis or similarly structured company to devise and implement a commonwealth-wide program evaluation system. This outcome system could then be imposed on the providers. One should note, however, a good evaluator would recognize that the outcomes of programs are expected to be different, and the evaluation system would have to take that into account. No system that assesses a single type of outcome would be acceptable.
- **6100.45, 5&7 – Satisfaction Surveys** – Everyone seems to like satisfaction surveys, but there are legitimate questions as to the validity of such endeavors. Remember that 87% of the families at Pennhurst were satisfied with Pennhurst. There is literature that suggests that there are “satisfied” people and there are “dissatisfied” people, and that the outcome of a satisfaction survey is largely a personality survey, rather than an objective assessment of any given situation. When I worked as a program evaluator, I recall that social workers loved any sort of training offered to them, and the psychologists hated everything. The ratings had nothing to do with the topic being offered, but everything to do with the person making the rating. And remember that a smart survey developer can easily shape the responses he/she will receive.
 - Recommendation – Drop all satisfaction surveys from the regulations, or continue to collect the data and throw it out immediately after collection.
- **6100.46 – Protective Services** – The requirement that the county be notified of incidents involving protective services could be considered a HIPAA violation unless the county has some responsibility for the person in question. In a state based system, an individual from Erie might live in Carlisle. I can understand the notification of Erie, but not Carlisle’s Cumberland County. They should have nothing to do with the individual, unless contracted otherwise.
 - Recommendation – delete county notification
 - Recommendation – add notification of the police in all cases
- **6100.47 – Criminal History checks** – Criminal history checks must be done on persons in any staff position, but only employees who provide reimbursed direct support are subject to the various hiring limitations imposed by law. If this is correct, why are we spending the money to do history checks on people who don’t work with consumers? This act potentially places the provider in jeopardy because if the provider doesn’t hire someone, it could be alleged that the provider did so because of the criminal history checks (which have in some cases found to be illegal).
 - Recommendation: restrict criminal history checks to those employees whose job actually requires these clearances.
- **6100.50 – Communication** – There is an implicit assumption that the mere presentation of instruction in the use of communication technology will enable all individuals to communicate. This represents yet another example of mythologizing the abilities of persons with intellectual disability. I agree that all should be provided with instruction and technologies, but I have a hard time accepting the notion that everyone will communicate with these supports. Again, individuals with intellectual disability are being treated as a monolith, rather than being recognized as individuals. Not everyone will ever “effectively communicate.”

- Recommendation - please insert phrases in the regulation that recognize that not everyone will be able to communicate (or make informed decisions or.....). Not everyone can do everything.
- **6100.51- Grievance** – There needs to be some recognition that some of the grievances coming from family are almost hallucinatory in nature. I am currently addressing a grievance from a mother who says that her son has shrunk 4” since admission. I have a state agency investigating me because an individual now attends school, wears clothing, and sleeps in her bed. Her mother is convinced that this could not have occurred without abuse. Another out of state agency is investigating an incident in which a staff saved an individual from drowning , but failed to document the rescue as a restraint. Allegations that reflect this degree of disturbed thinking take just as much time to resolve as do legitimate ones. There really needs to be a way to avoid the ridiculous allegations and grievances we receive.
 - Recommendation – the regulations need to include some way to quickly dismiss the grievances that totally lack credibility.
- **6100.502 – Rights Team** - The rights team , without any sort of relationship with the consumer and not required to have any sort of clinical expertise, is expected to make clinical recommendations including designing positive supports as an alternative to emergency restraint. The ethical shortcomings of treatment planning without a relationship are evident. The lack of a requirement for clinical expertise seems grossly in error. Most importantly, however, is the apparent confusion regarding what is a treatment and what is an emergency response. Years ago, contingent restraint was a treatment, and there is an empirical evidence base supporting its use. Danger and social acceptability now limit the use of restraint solely as an emergency procedure in Pennsylvania. It is no longer treatment in Pennsylvania. No treatment (positive or otherwise) is an alternative to an emergency response. It is like saying that a good diet and exercise will function as an alternative to the use of an aed device. In PA, restraint is not treatment; it is an emergency response. It does not belong in the PSP any more than the use of CPR or AEDs belong in the PSP.
 - Recommendation - The Rights Team should never make clinical suggestions. They lack the expertise. They lack the clinical relationship with the individual. To make such suggestions is grossly unethical.
 - Question – The rights team offers its recommendations to the PSP. Is the PSP under any obligation to follow the recommendations of these individuals who have no clinical expertise and who have no relationship to the individual?
- **6100.54 – Recordkeeping** - Section b places limits on to whom the consumer information may be made available. Notably missing from this list of agencies permitted accessed are the various disability rights agencies of different states and CMS.
 - Recommendation – add disability rights agencies and CMS (or not - better for providers if access is barred)
- **6100.181 – Exercise of Rights** – Section a indicates that a person may not be deprived of rights, yet there are mechanisms that allow us to deprive someone of rights. Consider an individual

with Prader Willi Syndrome. With approval of the PSP team, the kitchen can be locked to protect the individual. This maneuver, while permissible, is clearly a deprivation of rights.

- Recommendation – Don't overstate the case that a person cannot be deprived of rights. This is simply untrue. All of us can be deprived of our rights. Make reference to the due process that is necessary to deprive an individual of rights, or at least make reference to due process.
- **6100.181 – Exercise of Rights** – Section C implies that the proper supports and accommodation will enable an individual to understand and exercise his/her rights. This is yet another example of mythologizing the person with intellectual disability and of treating the intellectual disability population as a single common unit. Recognize individuality; some people will never be able to understand and exercise rights, no matter what resources are diverted to them.
 - Recommendation – be honest – not everyone can understand his/her rights
- **6100.181 – Exercise of rights** – no mention is made of Act 169. Act 169 permits the use of substitute health care decision makers (broadly defined in law) when two physicians question the individual's capability to make informed decisions.
 - Recommendation – add reference to act 169 in this section
- 1. **6100.182 – rights of individuals** – section e indicates that an individual has the right to make choices and accept risks. The regulation should clarify the extent to which a provider is responsible for the poor decisions of individuals. I've been in the witness stand trying to convince a jury of the dignity of risk; I can assure you that the argument doesn't play well to a jury.
 - Recommendation – providers should have indemnification language in the regulations that relieves them of responsibility for the poor decisions of people they support/serve. If we are to allow bad decisions to be made because of regulatory direction, we shouldn't be held accountable for the outcomes of those bad decisions.
- **6100.183 – additional rights** - This regulation pertains to the right to have guests in the home. Usually this is fine, but we have observed a number of incidents in which community people have sought to exploit consumers or whose presence in the home has annoyed or even threatened housemates. Is safety expected to be a standard applied here? Is there an expectation of protection to be provided by the provider?
 - Recommendation: please clarify limits. Can we bar dangerous people from the homes? More important, do we have a responsibility to ensure the safety of individuals from designing persons? Do we have immunity from lawsuits if we fail to offer protection because of the regulation?

- **6100.183 – Additional rights** – Section I states that an individual has the right to make informed health care decisions. As I understand rights, the individual also has the right to make stupid and uninformed health care decisions.
 - Recommendation – delete the word “informed” in every instance that it makes reference to decision making. I’m not sure that the word “informed” should appear in regulation.

- **6100.221 – Development of PSP** – Just so I understand this.... An individual who lives in a waiver group home under 6400 regulations and has employment through a 2380 licensed program will only need one treatment plan? And it will be coordinated? This would be wonderful. Is it your intent? What about IEPs? Can they be integrated into the PSP?
 - Recommendation – Please rewrite this section to be very clear (if there really is to be only one plan)

- **6100.221 – Development of PSP** – Section C states that the support coordinator or targeted support manager shall be responsible for development of the PSP.
 - Recommendation – Indicate that providers will not be responsible for the shortcomings of the PSPs because they didn’t develop them
 - Recommendation – Barring adoption of recommendation #1, I’d suggest that each provider be required to have a program specialist who is responsible for correcting errors in the PSP and for developing it when the supports coordinator is late.

- **6100.221 – Development of the PSP** – The initial PSP is developed prior to receiving services. All PSP are supposed to be based on current assessments. So if no one is getting paid to do the assessment, how is the plan to be completed? More importantly, how can a plan be developed if the team hasn’t had the time to assess and get to know the individual?
 - Recommendation – allow for a funded 30 day period to complete necessary assessment that will support the development of a valid treatment plan

- **6100.221 – Development of the PSP** – Section F indicates that the PSPs must be developed on current assessments. With regard to the Supports Intensity Scale, one would have to assume that current means one that was administered within only a few weeks of the plan because longer term stability of SIS scores have not been demonstrated empirically.
 - Recommendation – Define current as being within 30 days

- **6100.221 – Development of the PSP** – As written, it is conceivable that the PSP could go unaltered for 10 or more years. Annual review is not mentioned. Don't you want this? Somewhere later in the regulations is mention of an annual review. If that is accurate, it belongs in this section.
 - Recommendation – review of data on a monthly basis; team meeting every 6 months

- **6100.223 – content of PSP** – item #14 (modification of individual rights) is in conflict with 6100.181
 - Recommendation – revise 6100.181 to describe the due process that is needed to change/modify rights.

- **6100.223 – content of PSP** – Item 17 requires the team to delineate excluded, unnecessary, or inappropriate supports. There are supports that might be clinically appropriate but not permissible under PA regulations or not acceptable to the consenting party. Is this the type of information that should be included in this section?
 - Recommendation – I think this section #17 should be deleted. It places a tremendous liability on the provider if they identify a treatment that would work but fail to use for whatever reason.

- **6100.223 – content of PSP** – Signatures are required on the PSP, but one must recognize that many PSP teams will incorporate some form of teleconferencing. There must be some legitimate way for a person attending via teleconferencing to indicate his/her approval or participation. It would be ridiculous to mail the PSP to various members for signature.
 - Recommendation – adopt some sort of witnessed verbal consent or witnessed verbal indication of attendance.

- **6100.225 – Supports Coordination** – Because the supports coordinators do not work for the provider, the provider should not be held accountable for the work product of the supports coordinator. If any of the standards listed in this specific regulation are not met due to the unsatisfactory performance of a Supports Coordinator, there should be absolutely no consequences for the provider.
 - Recommendation – indicate that the provider is not responsible for the quality or timeliness of work products by the supports coordinator. Further, it should not be the responsibility of the provider to chase after a poor performing supports coordinator.

- **6100.226.e – Documentation of support delivery** – Gary Alexander was convinced that the intellectual disability system was rife with fraud, but he was unable to find any. Turns out providers are pretty honest. The documentation listed in section e seems like a massive overkill. What we do is not so complicated that it needs an excessively burdensome document system. I wonder if the costs of this documentation system outweigh the fraud that might occur in its absence.
 - Recommendation – let the provider set the prices for services, just as your local auto mechanic does. Let market competition get the price down to the lowest level. Why are we so hesitant to place faith in the free market?

- **6100.261 Access to the community** - This is the most interesting regulation in the entire package. It basically makes reference to some undefined unmeasured norm group. What is the normative target at which we are shooting? How often should one go to the movies? How often should one dine in a restaurant? Is the norm group the general population or the population of welfare recipients with IQs over 70? When I look at Core Indicator data, I find them interesting, but am left wondering what is the right answer. If you are going to reference some sort of normative standard, you really need to define that standard.
 - Recommendation – define what constitutes the “same degree of community access.”
- **6100.262.c – Employment** - reference is made in this reference to the annual PSP revision. I did not see reference to an annual revision. The regulation 6100.221 describes the initial PSP and PSPs schedule as needed or as requested by the individual
 - Recommendation – I think there should be a meeting every 6 months, supplemented by monthly data reviews.
- **6100.263 – Education** - no mention is made of school and the IEP process. It must be recognized that there will be school age children living in some 6400 licensed homes that are funded via base funding and who still have a school entitlement. Somehow this should be acknowledged in the regulation
 - Recommendation – acknowledge that some individuals living in homes covered by these regulations will still have some school entitlement, and that entitlement must be respected. I don’t imagine that the IEP and PSP can be merged into a single document, but there must be recognition of the school entitlement.
- **6100.303 – Reasons for transfer** – The reasons for an involuntary transfer are reasonable, but fail to include the instance in which the provider is not being paid (inadequately or at all) by the funding agency. There must be an option for transfer/discharge when the provider is not being compensated for his/her efforts. Let us not forget the dreaded RAF of a couple of years ago.
 - Recommendation – add to the list of reasons for involuntary transfer that the provider is not being fully compensated for the necessary services
- **6100.304 – written notice** – when a provider concludes that it must discharge/transfer an individual, it is typically an emergency decision. A forty-five day notice, as required under these regulations, fails to recognize the possible risks that are associated with such a delay. Arguably, even 45 days is wishful thinking. From what I’ve seen the discharge process can take years. But 45 days says that this is not a rush to the Commonwealth.
 - Recommendation – reduce the time frame to 10 days. Such discharges are typically emergency decisions, not casual ones.
- **6100.341.b – Use of positive interventions** - provider is required to use the least intrusive method when treating an individual with a behavior problem. This regulation potentially forces a clinician to engage in non-evidence based practice by selecting treatment on intrusiveness rather than efficacy. Further, the regulation ignores contemporary thought in treatment selection. Jon Bailey (2015) , in his book on ethical behavior change strategies, adopted Spreat’s (1982) guidelines that treatment selection should be based on a simultaneous consideration of 1)probability of treatment success, 2)

distress caused by the treatment, 3) distress caused by the continued expression of the behavior, and 4) time until the treatment changes the behavior. Note also that to impose a requirement that least intrusive treatment be used first may also violate an individual's right to participate in the selection of treatment options. Suppose a consumer chooses the more "intrusive" time out over redirection?

- Recommendation – instead of mandating the least intrusive method, the regulation should state the clinician shall exercise professional judgment in making treatment recommendations, simultaneously considering 1) probability of treatment success, 2) distress caused by the treatment, 3) distress caused by the continuation of the behavior, 4) time until the treatment changes the behavior, and 5) preferences of the individual and/or his/her guardian. The decision to accept or reject the recommendation would seem to fall to the consumer or his/her guardian or substitute health care decision maker.
- **6100.342 – PSP** – congratulations on the recognition that the use of emergency restraints is not a treatment option and does not belong in the PSP. Use of emergency restraint is not among the required 7 elements of the treatment plan, although there is recognition that there are circumstances that might require use of such restraint. I hope that I have read this regulation correctly.
 - Recommendation – good job – maybe make it more clear that restraint use is not part of the behavior program in the PSP.
- **6100.343.5.i – prohibition of restraints** - permitted are devices used to provide post-surgical care and several others conditions. It would appear that the use of a device to allow healing of something less than surgery would be forbidden, as would a cast for a broken arm that didn't actually require surgery.
 - Recommendation – broaden the definition to include devices that allow healing to occur and allow the use of casts
- **6100.345 – access to individual's personal property** – Individual funds should not be used as payment for damages. An exception should be added such that the rental agreement referenced later in the regulations may include a security deposit that can be used to remedy damages to the building. I'm not sure how allowing an individual to evade a personal responsibility is consistent with the notion of Everyday Lives.
 - Recommendation – please include the possibility of a security deposit as an exception to bans on the use of individual's property.
- **6100.402 – incident investigations** – investigations are now required of all incidents, including the use of restraints. The regulations once again fail to consider the heterogeneity of the population we serve. Those programs that serve/support individuals with dual diagnoses will inevitably be conducting many investigations of legitimate emergency restraint use. Frankly, this will be a waste of time and money. It will require dual diagnosis programs to hire extra investigators in order to comply, and I hope that the Commonwealth will pay for these extra employees.
 - Recommendation – recognize the heterogeneity of our service population, and adjust regulations accordingly. To that end, recommend a monthly summary of restraint use, rather than an investigation of every single restraint use.
- **6100.404 – final incident report** – The regulation requires a final incident report within 30 days of the incident. If the individual alleged to have been abused is under 18, child welfare officials will be

involved. They are permitted up to 60 days to complete their investigation. Generally, we are unable to conclude our investigation until Children and Youth complete theirs. The 30 day limitation imposed in 404a will sometimes be unworkable.

- Recommendation – recognize the child welfare time limits and allow 75 days to complete an investigation when a child is involved.
- **6100.405 – incident analysis** – This item requires that a root cause analysis be completed for each confirmed incident. Do you mean to include every confirmed incident? We'll be doing hundreds of root cause analyses each year. Do we do a root cause analysis of why someone fell off a bike and scraped their knee, requiring a trip to the emergency room? This seems excessive. Also, root cause analysis is a technical analysis that really requires some significant training for the person conducting the analysis. Will the department be providing training in root cause analysis to prepare people to do a minimally competent job? Will we be expected to hire additional staff with training in root cause analysis?
 - Recommendation – delete the term “root cause” because it has precise meaning beyond merely trying to figure out why the incident occurred. Alternately, provide training/certification in root cause analysis and compensate programs for conducting root cause analyses.
- **6100.442 – Physical Accessibility** – The regulation states that the provider will arrange for accommodations and equipment to meeting health, safety, and mobility needs of individuals. This is reasonable, but I question why sprinkling the building is not listed as a safety need. Perhaps it appears elsewhere in the regulations.
 - Recommendation – add sprinkling the building as a safety measure.
- **6100.444 – lease or ownership** – protections are listed for individuals living in the home. The regulation needs to recognize protections for the landlord which are part of PA landlord-tenant law. It should be clearly stated that landlord rights, as recognized in PA, will pertain here.
 - Recommendation – recognize landlord rights, including right to a security deposit and the right to evict
- **6100.446 – Facility Characteristics** - this regulation limits new day programs to a maximum of capacity of 15. I understand the general logic of small being better in residential areas, but I'm not sure why this standard is applied to day programming. I personally work with about 1800 colleagues. I have to assume that the Commonwealth recognizes that no agency will make any money with just 15 customers and will, thus, have to close. Day care programs for children typically take around 60 kids to break even.
 - Recommendation – set a realistic census capacity, unless, of course, that your goal is to drive everyone out of the day program business.
- **6100.465 – prescription medication** – Section A requires prescriptions to be done in writing. Many agencies are moving to electronic prescription, and there will be no traditional signatures. This should be recognized.
 - Recommendation – drop requirement for written prescriptions if the agency or physician uses an electronic prescribing process.

- **6100.466 – medication records** – Item a11 makes reference to PRN medications. I would recommend forbidding the use of most PRN medications, particularly in community homes.
 - Recommendations – forbid use of PRN medication

- **6100.481 – Department rates and classifications** – It is just so wrong that the purchaser of services gets to set the price of the service, without even consulting or negotiating with the seller. I don't imagine that the state gets to set the price for Morrisey to build a new road. Prices are supposed to be either set by the seller or negotiated between the seller and purchaser. The failure to include an option for the provider to set a price, to be accepted, rejected, or negotiated by the purchaser just seems to violate basic free market principles.
 - Recommendation – add seller set prices as one method of establishing prices for services.

- **6100.481 – Department rates and classifications** – I note the punishments that may be imposed on providers, what about punishments for the Commonwealth for late payment? I'm thinking of something like 18% interest on bills not paid within 30 days of submission.
 - Recommendation – add a provision that the Commonwealth will pay 18% annual interest rate on any properly submitted bill that is not paid within 30 days.

- **6100.482.h – Payment** – As I read section H, the section effectively bans fundraising or the operation of for profit businesses to supplement underpayment from the Commonwealth. So if the Commonwealth doesn't pay the full real cost of service or if the Commonwealth introduces another retroactive RAF, there is absolutely no way for the provider to make up the difference.
 - Recommendation – guarantee that there will never be a retroactive RAF again
 - Recommendation – guarantee that the Commonwealth will pay the full cost of all services purchased.

- **6100.483 – title of a residential building** – Whoa! Is this just a sneaky way for the Commonwealth to regain ownership of all partially paid for homes and all future homes? Homes are what constitute much of our net assets and allow us to borrow money. Take away our homes, and we will be unable to borrow, and perhaps have existing loans called. I seem to recall Kevin Casey deciding that the providers would own the homes. This looks like a plan for out and out theft.
 - Recommendation – I suspect that going forward on the purchase of new homes, the Commonwealth can take ownership. And I assume that this ownership will come with the responsibility to maintain the home. This would not be great. When I worked for Temple, I was Director of Woodhaven Center. The state actually owned the buildings, and it did a poor job of maintaining the property. I would not want to operate a home owned by the commonwealth, nor would I want to use my company money to maintain the commonwealth's property.
 - Recommendation – Homes purchased by providers belong to the providers. When a mortgage is active, the provider will own all equity in the home, not the Commonwealth.
 - Recommendation – if the home is owned by the commonwealth, then I would have to assume that any lease or rental agreement with the consumer would have to be with the commonwealth rather than the provider.

- **6100.486 – bidding** – I would suggest caution in accepting the lowest bid. We accepted the lowest bid on a building, and we are now suing the builder for the corners he took and that we had to pay to correct. Not sure prudent buyer is enough of a protection.

- Recommendation - Continue with the bidding process, but do not expect the provider to accept the lowest bid. Require providers to have a policy on purchasing.
- **6100.571 – fee schedule rates** – the market based approach says that employee wages must be one of the factors used to set fee schedule rates. This approach would be accurate only in the situation of zero turnover and zero vacancies in staffing. Turnover and vacancies result in overtime use and/or the use of temp staffing, both of which cost more than just staff wages. Even staff wages cost about another 28% on top of the actual wage. The real issue is what does it cost a provider to fill a slot on an hourly basis, and in situations of some vacancies and high turnover, it will be considerably higher than the mean staff wage. The appropriate dependent measure here is the hourly cost of an employee, not their hourly wage.
 - Recommendation – rather than employee wages, require the use of the cost to fill an employee slot in the calculation of rates.
- **6100.571 – fee schedule rates c1** – another factor for setting rates is the support needs of the individual. The mechanism for establishing the support needs should be explicated. Does this mean the SIS plus Oregon questions?
 - Recommendation – SIS scores should be jointly determined by the Commonwealth and the provider.
- **6100.642.c - assignment of rate** – this regulation states that a new provider will be assigned the area adjusted average rate of approved provider cost based rates. This would seem to guarantee that no new providers will enter the area. I have avoided entering the waiver program in Bucks County because it would probably require me to lose money for two years with no guarantee that the commonwealth would ever make me whole.
 - Recommendation - If we can't adopt the free market approach of letting the seller set the price, can't we at least use the same calculation process as is used by existing providers.
- **6100.644.a – cost report** –
 - Question - what is the allowable administrative cost of the HCBS?
- **6100.645.f – rate setting** - it is nice that there will be a notice of the rate setting methodology, but there must also be time for comment
 - Recommendation – note that the rate setting methodology published in the Bulletin will be printed in such time as to permit the opportunity for the public to comment on the rates.
- **6100.646.b – Cost based rates** - an outlier is defined as 1 standard deviation beyond the mean. It should be noted that 16% of all costs will be above the mean (if the distribution is normal; if not normal, SD means nothing), and 16% of costs will be below the mean. This means that you are defining about 1/3 of all costs as outliers. This seems pretty excessive
 - Recommendation – Define outlier as more than 2 standard deviations beyond the mean. This will limit the identification of outliers to just 4%
- **6100.646.c –Cost Based Rates** – A vacancy factor will be applied, but you haven't indicated what that vacancy factor will be. This was one of the key issues in the threatened PAR litigation. I don't see how you can't have this in regulation. Otherwise, you can do whatever you want, and PAR will probably sue.

- Recommendation – identify the vacancy factor in the regulation. Clarify how it is calculated.
- **6100.659.b.1 – Real estate taxes** – Real estate taxes are apparently an allowable cost. I’m not sure how this can be justified when state law allows non-profits to not pay real estate taxes. While I can understand the rationale from a township’s perspective, state law allows non-profits to not pay taxes. If you are going to allow for taxes, will you also allow for payments made in lieu of taxes?
 - Recommendations – I fear that this is a slippery slope. If group homes should pay taxes, why not hospitals, universities, and churches? I would recommend dropping the allowance for real estate taxes and taking a strong stand that non-profits don’t have to pay real estate taxes or fees or payments in lieu of taxes.
- **6100.664.a – residential habilitation vacancy** - the regulation states that the department will set a vacancy rate. Where is it? What is it? How will it be calculated? This is one of the three pinions of the PAR lawsuit. It needs a better answer.
 - Recommendation – vacancy rate cannot be left open to manipulation. State what the vacancy rate will be, or at the very least, state how it will be calculated. Let us note that vacancy rate was one of the three pillars of the threatened PAR lawsuit.
- **6100.668 – insurance** – the regulation lists a number of allowable insurances. Notably absent are malpractice insurance and insurance for Board members.
 - Recommendation – add malpractice insurance and board and director’s insurance.
- **6100.668 Insurance** - it seems unthinkable that legal costs to prosecute a claim against the commonwealth are not allowable, particularly after the mistreatment of providers under Gary Alexander’s regime. The Commonwealth does not have such a sterling reputation that it should be afforded this sort of courtesy.
 - Recommendation – costs of prosecuting a claim against the Commonwealth must be allowable expenses.
- **6100.686 – Room and Board** – it appears that room and board will be limited to 72% of SSI. Individual SSI is \$733/month, so room and board will be about \$528 per month. Let us assume that board (food) is about \$8/day, or \$240 per month. That will leave just \$288 per month for room (rent). With 4 people in a house, the total rent would be only \$960. This amount would qualify for a home purchase of just \$200,000. This is generally inadequate in all but Perry County.
 - Recommendation – Board payments, from whatever source, must be sufficient to enable individuals to live in safe, relatively decent housing. \$960 per month is insufficient.
- **6100.688 –room and board residency agreement** – I am concerned that the Department specifies the form of residency agreement to be used. This is a business arrangement, and the landlord must be protected as well as the tenant. There is little reason to believe that the Commonwealth will have the providers interests in mind. It is a legal contract, and must be negotiated according to best legal practices. My understanding is that a one sided contract is not valid.
 - Recommendation: - The room and board agreement must be mutually acceptable to both the commonwealth and the provider. It must be subject to review by the provider’s attorney and subject to modification on a case by case basis.

- **6100.711.d.1- fees for ineligible** – Staff wages are factors to be considered in setting fees. This is in error. It should not be wages, but rather the cost of filling the staff slot. This will be higher because it takes into account overtime, vacancies, turnover, vacations, sick leave, and costs of temporary staff. Cost of filling a slot will invariably be higher than mean hourly wage.
 - Recommendation – The cost of filling a slot should be the basis considered for setting fees, rather than mean hourly DSP wage.

- **6100.741 – Sanctions** – There is a whole list of sanctions that may be levied against the provider, but nothing that will be levied against the Commonwealth. There is no prohibition against the Commonwealth electing to not pay or for electing to reduce payments (as in the historic RAF).
 - Recommendation: There must be sanctions to hold the Commonwealth accountable. There should be penalties for late payments. I am suggesting an 18% annual percentage rate for any bill not paid within 30 days.
 - Recommendation: There should be an explicit prohibition of any negative rate adjustments.

6400 regulations

General Comments

Issue #1 – HIPAA violations are mandated – Per 6400.18, incident reports are to be shared with the county in which the program resides and the individual's family or guardian. Given that we no longer operate a county based system and given that a number of 6400 licensed homes serve/support individuals from other states, mandating a report to the county could easily be considered a HIPAA violation. I am in Bucks County, and I don't see that Bucks County has an entitlement to information regarding an individual from NJ and funded by NJ. PA, because it licenses me, has an entitlement to that information, but Bucks County does not. Notifying parents can create another problem, unless the individual has authorized the release of this information to the parents. Without a court order, parents of adults have no right to information regarding their adult children. Act 169 might provide an alternative that would get around the HIPAA violation, but its use would have to be encouraged.

Issue #2 – Failure to recognize the heterogeneity of our service population - It must be recognized that our service/support system works with individuals who display a wide range of skills and abilities. In my own program, I have people living semi-independently in apartments, and I have people with extensive support needs. While some of these support needs are medical in nature, many are behavioral. Our program has been developed to serve/support individuals who have intellectual disability/autism concomitant with significant aggression, self-injury, or other mental health challenges. The term dual diagnosis is sometimes used to describe this population.

The problem is that some regulations that will work well for the general bulk of the population will not be as workable for other parts of the population. The typical person with intellectual disability does not have significant behavior problems, and will be unlikely to experience restraint. For a program supporting such an individual, the investigation of every restraint and the formation of a rights review committee will not be a significant issue. For those programs in PA that specialize in serving/supporting individuals who have dual diagnoses, investigating every instance of restraint will be overwhelming.

You can't realistically write regulations without consideration of the outliers. There either needs to be specific regulations directed to dual diagnosis programs, or there must be a clear invitation to submit waiver requests for the more odious regulations. The issue is not limited just to restraint use. Each of the regulations need to be reviewed from the perspective of asking whether the regulation will be workable for the extreme tails of the population. Most of the regulations are fine, but they fail to consider how they will impact programs supporting/serving individuals with more unique needs.

Issue #3 – The proposed regulations, in an effort to recognize the rights of all, ultimately create a myth of the person with intellectual disability. For example, Exercise of Rights (c) suggests that the provision of support and accommodation will enable an individual with intellectual disability to understand and exercise his/her rights. Perhaps this is true for most individuals with intellectual disability (note that most individuals with intellectual disability have mild intellectual disability), but it is frankly an impossibility with those individuals who face more significant cognitive challenges. Again, the problem derives from considering the intellectual disability population as a monolithic group of people with similar needs and skills. Wanting everyone to be able to exercise his/her rights is a nice wish, but not one that is supported by reality.

Issue #4 – Abandonment - It has been our experience that not all funding agencies honor their fiscal commitments to providers. I currently have eight individuals who have no funding and 2 or 3 additional individuals whose funders have elected to no longer pay (and this doesn't count the number of funders who elect to give themselves a discounted rate). A provider can't really be expected to absorb so many individuals who have no funding, but this regulation would appear to give them no option but to retain these unfunded individuals. If we were to discharge them to a shelter, we could be cited for abandonment. Perhaps the abandonment regulation should be focused on those funders who fail to fund the individuals they place.

Issue #5 – Concerns regarding treatment selection – The regulation on page 267 states that the least intrusive method will be applied when addressing a dangerous behavior. First, it is not clear whether this standard pertains to treatment selection (as is changing the future probability of the behavior) or emergency situations. In either case, consideration does not appear to have been given to the issue of efficacy. Forcing a clinician to recommend minimally intrusive interventions can create an ethical dilemma for the clinician whose professional judgment is that the minimally intrusive intervention will not successfully change the behavior. Treatment selection requires simultaneous consideration of 1) probability of treatment success, 2) distress caused by the treatment, 3) distress caused by the continued expression of the behavior, and 4) time until the treatment changes the behavior. This model for treatment selection was put forth in Axelrod, Spreat, Moyer, and Berry and further refined by Jon Bailey in his book on behavioral ethics. Authors were clear in pointing out that to choose a treatment solely on the basis of intrusiveness would be unethical. Note also that to impose a requirement that least intrusive treatment be used first may violate an individual's right to participate in the selection of treatment options. Suppose a consumer choose time out over a redirection?

Issue #6 – Rights Team - The rights team, without any sort of relationship with the consumer and not required to have any clinical expertise, is expected to make clinical recommendations including designing positive supports as an alternative to emergency restraint. The ethical shortcomings of treatment planning without a relationship are evident. The lack of a requirement for clinical expertise seems grossly in error. Most importantly, however, is the apparent confusion regarding what is a treatment and what is an emergency response. Years ago, contingent restraint was a treatment, and there is an empirical evidence base supporting its use. Danger and social acceptability now limit the use of restraint solely as an emergency in Pennsylvania. It is no longer treatment. No treatment (positive or otherwise) is an alternative to an emergency response. It is like saying that a good diet and exercise will function as an alternative to the use of an aed device. In PA, restraint is not treatment; it is an emergency response. It does not belong in the PSP any more than the use of CPR or AEDs belong in the PSP.

Specific Comments

- **6400.1** – While it isn't out of line to apply the principle of normalization to people with autism, I don't recall it being part of the common application of the principle. Perhaps recognition of this and justification for the application might be given.
- **6400.2** – purpose of the chapter is to protect the health, safety, and well being of individuals. Is it then appropriate to judge each of the following regulations by these three standards, deleting any proposed regulation that doesn't protect health, safety, or well being?
 - Recommendation – delete the limiting reference because the regulation go well beyond health, safety, and well being, or....
 - Recommendation – review each proposed regulation from the standard of whether that regulations promotes health, safety, or well-being, and delete any proposed regulation that fails to do that.
- **6400.3** – stuff seems to be missing here
- **6400.4** – The term autism is said to include “asperger’s disorder,” however, the most recent version of the DSM eliminated this term from the diagnosis of autism.
 - Recommendation- delete reference to aspergers disorder
- **6400.4 – ISP** – I thought you were changing the name to Person center Service Plan? I think this may just reflect my confusion with your presentation of changed and unchanged regulations.
 - Recommendation – use the term Person Center Service/support plan consistently in the documents
- **6400.18.c** – the required notifications would seem to be a violation of HIPAA for Out of State clients or for clients not funded by the county or ODP.
 - Recommendation – change the notification guideline to require notification to require notification of the funding agency
- **6400.18.c** – asides from the HIPAA violation, since we are now a state based system, what right does the county have to this information anyway? The individual might live in Chester County but was placed by Erie County. I can see the appropriateness of notifying Erie County, but why Chester?
 - Recommendation – delete requirement to notify any county because we are not a county based system. The only exception would be for county base funded consumers
- **6400.18.e** – again, a HIPAA violation for Out of state clients and persons not funded by county or ODP.
- **6400.18.h** – Another potential HIPAA violation if the individual (who is an adult) has not authorized the notification of the family.
 - Recommendation - Notify the family if so directed (or pre-directed) by the consumer. Notify any other consistent with Act 169 if the consumer is incapable of making or communicating communication preferences

- **6400.20.f** – This document fails to recognize the diversity of individuals served under these regulations. To require an investigation of every restraint is reasonable in a program whose consumers don't engage in behaviors that warrant more than rare restraint use. Programs that specialize in consumers with significant behavioral or mental health involvement will be grossly overburdened by this requirement. It may lead them to rethink their willingness to serve individuals who have significant behavioral involvement. The regulation fails to recognize the diversity of the population served. While most individuals with intellectual disability do not engage in significant behaviors, there is a significant subpopulation that does so engage. To punish programs who electively serve/support individuals with challenges benefits no one.
 - Recommendation: The commonwealth should introduce an incentive for the production of investigations, such that each investigation report resulted in \$1000 to the agency producing the report. This would reduce the burden on dual diagnosis programs, by allowing them to hire additional staff to do all of the reports.

- **6400.20.a.1** – A root cause analysis shall be completed for each confirmed incident. Do you mean to include every confirmed incident? Do we do a root cause analysis of why someone fell off a bike, scraping their knee and requiring a trip to the ER? This seems excessive. Also, root cause analysis is a technical analysis that really requires some significant training for the person conducting the analysis. Will the department be providing training in root cause analysis to prepare people to do a minimally competent job?
 - Recommendation – delete the term “root cause” because it has precise meaning beyond merely trying to figure out why the incident occurred. Alternately, provide training/certification in root cause analysis and compensate programs for conducting root cause analyses.

- **6400.32** – the regulation says that people may not be deprived of rights, but people are deprived of rights all the time. Think of the police and the judicial system. If deprivation of rights weren't an issue, we wouldn't need the ACLU. The regulation needs to be focused on those controlled by the regulations.
 - Recommendation – Change the regulation to “A service provider may not deprive an individual of rights without due process as defined by these regulations.”

- **6400.33** – There is a listing of consumer rights. Does the individual also have the right to refuse to participate in programming?
 - Recommendation – add that the individual has the right to elect to not participate in any programming
 - Recommendation – add that the individual (or guardian or act 169 substitute health care decision maker) has the right to reject medical recommendations. This will eliminate the ethical dilemmas placed on physicians when patients/guardians refuse sound medical recommendations.

- **6400.34.c** – This regulation implies that in all cases, it is possible to enable an individual to understand and exercise his/her rights. This regulation creates a mythological individual in many cases. It is simply not a complete possibility.
 - Recommendation: add “to the extent possible given the individuals cognitive limitations” to the end of the regulation. We need to be honest that there are people for whom understanding and acting on rights is an impossibility.

- **6400.32.d** – Our society routinely punishes and retaliates for the exercise of rights. The regulation needs to be focused on the providers.
 - Recommendation – change to “An individual may not be reprimanded, punished, or retaliated against for exercising the individuals’ rights by the provider.”
 - Recommendation: rewrite the standard to eliminate the dangling preposition of against
- **6400.32.** – Mention is made of legally appointed guardians, but no mention is made of Act 169 recognized substitute health care decision makers
 - Recommendation – add an additional standard that recognizes those substitute decision makers established through Act 169 procedures.
- **6400.32** – An individual may not be abandoned. This term needs some sort of definition. Consider the provider who has not been paid for services (I currently have 8 unfunded consumers). Does this regulation forbid me from discharging those individuals?
 - Recommendation – define abandonment such that it excludes discharging the individual for lack of payment,
- **6400.32.f** – an individual has the right to refuse to participate in treatment. This seems fine. Is there a point, however, at which the funder or provider would say that the individual’s decision to not participate warrants service discontinuation? Why should the commonwealth pay for someone to sit and do nothing?
 - Recommendation: please clarify whether there are limits on this right
- **6400.32.i** – This regulation pertains to the right to have guests in the home. Usually this is fine, but we have observed a number of incidents in which community people have sought to exploit consumers or whose presence in the home has annoyed or even threatened housemates. Is safety expected to be a standard applied here? Is there an expectation of protection to be provided by the provider?
 - Recommendation: please clarify limits. Can we bar dangerous people from the homes? More important, do we have a responsibility to ensure the safety of individuals from designing persons? Do we have immunity from lawsuits if we fail to offer protection because of the regulation?
- **6400.32.n** – Individual is entitled to access to telecommunications. Does this imply that the provider must provide internet access, or does it mean that we simply must not interfere? If we learn that the individual is engaging in unsafe or illegal telecommunication practices, do we incur some sort of responsibility to protect them.
 - Recommendation: please clarify
- **6400.32.r** – I guess you’ll get enough comments about the danger of allowing consumers to lock their bedroom doors that I’ll let this one ride
- **6400.32.s** – Access to food. I suppose that waivers can be requested for people with Prader Willi Syndrome, but what about other weight issues. I was once an expert witness on behalf on an agency that essentially allowed an individual to eat and gain weight to the point that his health was jeopardized and he ultimately died. Will this regulation function as an indemnification in court proceedings when a provider is sued for the overeating death of a consumer?

- **6400.32.t** – Of course an individual has the right to make “informed” health care decision. The real test is whether they can make uninformed health care decisions. Not everyone is capable of making informed decisions.
 - Recommendation – delete the word “informed”
- **6400.44** – program specialist
 - Recommendation: add a standard that would state that the program specialist is responsible for correcting the work of the supports coordinator to ensure a quality PSP product. This would include completely doing the PSP when the supports coordinator fails to meet mandatory timelines.
- **6400.165** – Prescription orders must be in writing. As more and more physicians are going to an electronic health record that is supported by electronic prescriptions, the need for a “written” prescription is anachronistic. A state of the art medical office can entirely function in a paperless manner, contacting pharmacies directly to order medications. Why should we punish a provider for selecting physician who has gone paperless?
 - Recommendation – delete the requirement for a written prescription
- **6400.166.11** – are you really going to allow PRN medications?
 - Recommendation: delete prn medication use
- **Development of PSP.f** – The standard says that the individual and persons designated by the individual shall be involved in the development of the PSP. This has the potential of creating a problem. In some cases, the individual’s guardian (or Act 169 substitute decision maker) will designate the involvement of the CEO as a member of the team. If I refuse to participate in teams, it appears that I could get cited under this act. There must be limits on who can be designated. This is already a problem with some families that feel entitled to having the highest authority present. Making this a regulatory standard means that CEOs and COOs will spend all of their time at team meetings. A second concern is that theoretically, an individual could refuse to designate participants who actually provide supports and services to the individual.
 - Recommendation: place some limits on who may be invited. Ensure that persons providing supports/services are involved in the team
- **6400.183.c** – persons who attend the PSP meeting must sign and date the PSP. What about persons who attend the meeting electronically? Will some sort of substitute signature be permitted? May someone sign on their behalf?
 - Recommendation: recognize that some team meetings will be facilitated by telecommunication, and that active team participants via telecommunication may be unable to actually sign the document. Make some sort of allowance for this. I’m not real sure why the signatures is such a big deal anyway. The team lists participants. It seems like a way for licensing officials to catch providers, rather than any act that protects the health, safety, or well being of consumers.
- **6400.184.2** – Again there is reference to “informed” decisions. First, it is presumptuous to assume that everyone is capable of making informed decisions, and second, I’m not real sure why any

decision has to be informed if you are really interested in rights. A person has the right to make a dumb uninformed decision.

- Recommendation: remove the term “informed”
- **6400.185.10** – the regulation implies that there are ways to modify an individual’s rights, but this is in direct conflict with “Exercise of rights.a” which says that a person can’t be deprived of rights. This one makes more sense, but you have conflict. This places a provider in jeopardy to the whims of licensing officials.
 - Recommendation: revised “Exercise of Rights. A” to recognize that there is a way to modify an individual’s rights
- **Use of a positive intervention (p. 267)** – The regulatory standard states that the least intrusive methods shall be applied when addressing a dangerous behavior. No consideration is given to the issue of efficacy, forcing clinicians to recommend minimally intrusive interventions that they might not believe will work. There is an ethical dimension to selection among treatment options, requiring a mutual consideration of 1) probability of the treatment being successful, 2) distress caused to the individual by the behavior, 3) distress caused to the individual by the treatment, 4) likely duration of treatment. This model is presented in Axelrod, Spreat, Moyer, and Berry (year?) and refined and restated by John Bailey on his book on behavioral ethics. It should be noted that one might argue that to recommend a treatment based solely on intrusiveness could easily be considered unethical.
 - Recommendation- delete the use of the term “least intrusive.” Replace is with something like “least intrusive intervention with a reasonable likelihood of success.”
- **6400.193.5.i** – The regulation provides a for the use of protective devices for a limited number of conditions. Notably missing from the exclusions are devices that are provided/applied to enable a wound to heal and casts for broken bones that did not require surgery.
 - Recommendation – permit casts; permit devices designed to protect an individual while a wound heals.
- **6400.1933** – don’t you want to ban basketholds, too?
 - Recommendation: ban the use of basketholds because they have the potential for compromising an individual’s ability to breathe.
- **6400.194.c** – This regulation refers to training to use emergency personal restraints. Must the training be individualized to the person being restrained? Or may generic training in 2-4 person prone restraints be used?
 - Recommendation: All persons working with an individual should be trained in his/her PSP. Emergency restraint is not a form of treatment. Like the use of CPR, it is an emergency response. It does not belong in the PSP. If a person is trained in 2-4 person prone restraint, they should be allowed to assist in any 2-4 person restraint, but they should not be the restraint leader unless they have been trained in the PSP. Otherwise, the regulations create a “gotcha” in which inspectors will look to see if they can find a violation in a person who helps in a restraint. Note that one doesn’t have to be trained in John’s AED protocol in order to use an AED with John.

- **6400.194.f** – the 15 minute limitation on the use of a personal restraint begs the question of what one is to do with a violent individual at the end of 15 minutes if they are still being assaultive.
 - Recommendation: Maybe offer a suggestion of what to do after 15 minutes? Call 911?
- **6400.195.b** - an individual's funds may not be used as payment for damages. How does this affect the construction of leases? Are security deposits forbidden because of this regulation? It seems that this regulation enables an individual to avoid some of the responsibilities of Everyday Lives.
 - Recommendation: Revise this regulation to permit the landlord (provider) to withhold funds from a security deposit, as is the case with the rest of the rental world.
- **6400.196 – rights team** – a right team will review each incidence of emergency restraint. For agencies that specialize in serving individuals with severe behavior challenges, this will become an odious task. The regulations are failing to view persons with disabilities as a heterogeneous group, and that a regulation that might be fine for part of the group will be burdensome to another.
 - Recommendation: create a different form of review for dual diagnosis programs
- **6400.196.b.ii** – The rights team , without any sort of relationship with the consumer and not required to have any clinical expertise, is expected to make recommendations including designing positive supports as an alternative to emergency restraint. The ethical shortcomings of treatment planning without a relationship are evident. The lack of a requirement for clinical expertise seems grossly in error. Most importantly, however, is the apparent confusion regarding what is a treatment and what is an emergency response. Years ago, contingent restraint was a treatment, and there is an empirical evidence base supporting its use. Danger and social acceptability now limit the use of restraint solely as an emergency in Pennsylvania. It is no longer treatment. No treatment (positive or otherwise) is an alternative to an emergency response. It is like saying that a good diet and exercise will function as an alternative to the use of an aed device. In PA, restraint is not treatment.