

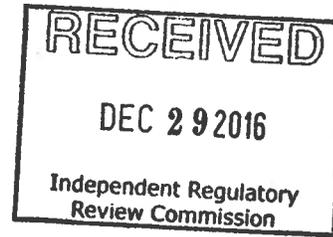
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Kroh, Karen

From: Mochon, Julie
Sent: Wednesday, December 21, 2016 8:57 AM
To: Kroh, Karen
Subject: FW: Comments to 6100
Attachments: ch6100comments.letter.dotx; VisionforEquality.6100.comments.docx

From: Lisa Tesler [<mailto:ltesler@visionforequality.org>]
Sent: Tuesday, December 20, 2016 10:03 PM
To: Mochon, Julie
Cc: Audrey Coccia; Maureen Devaney; Lisa Tesler
Subject: Comments to 6100



Julie,

Please see attached letter and comments from Vision for Equality.

Thanks,
Lisa

Lisa Tesler
Director



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Vision for Equality

Serving People with Disabilities and Their Families

December 20, 2016

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,

Vision for Equality appreciates the opportunity to provide input regarding the proposed Chapter 6100 regulations governing Home and Community Based Services provided through the Office of Developmental Programs. Our Mission is to assist and empower people with disabilities and their families to seek quality and satisfaction in their lives as well as equal access to supports and services.

Our goal is assure that the system is easy to access, responsive to individuals and their families, respectful of individual rights and the important role of family, focused on their needs and truly centered on full integration and community engagement. The services provided should allow maximum flexibility and control for individuals and their families. The AEs, Supports Coordination Organizations, and the provider network have a responsibility to provide families the type of support they need, when they need it, where they need it, in the community of their choosing.

Families are the backbone of the system. Over 70% of people with disabilities live at home with their families and we should support them in a way that makes their lives successful. We are seeking a system that is responsive to people and their family's needs. People and their families are seeking an *Everyday Life* – a life well lived in their homes and communities. They seek a service system that is welcoming to everyone – no matter what their ability.

Thank you for your time and consideration in this matter. We are available to answer any questions and discuss these specific recommendations with you. We look forward to continuing to work with the Office of Developmental Programs during the waiver renewal process to represent the voice and needs of individuals with intellectual disabilities and autism and their families.

Sincerely,

Maureen Devaney
Co-Executive Director

Audrey Coccia
Co-Executive Director

Vision for Equality

December 20, 2016

Comments to Proposed 6100 Regulations

General Comments

We applaud the effort to adopt Chapter 6100 Regulations, while concurrently amending Chapters 2380, 2390, 6400, and 6500. We are hopeful that consistent rules and the elimination of duplicate or conflicting requirements assure that all people are afforded the same rights and protections, regardless of where they live or how they are supported. We support consistency across programs to eliminate the confusion faced by families who navigate through the systems. That said, we have limited capacity to review and comment on each section of the proposed rulemaking, therefore, we have focused our energy and time on the Chapter 6100 language but our comments apply to the relevant related sections of Chapters 2380, 2390, 6400 and 6500.

We are encouraged by the language included that ensures individual rights and Person-Centered Planning. We support the inclusion of autism services within these regulations, as we believe all individuals deserve protections and support, regardless of their diagnosis.

We support inclusion for all people in the broader community, but we need to assure that the financial resources necessary are available to this mission.

Additionally, children supported by the ODP programs must be considered in the regulations. We support the inclusion of permanency planning for children who are living in residential service locations. We support requirements for children to be able to access appropriate education supports through the local public school district.

Chapter 6100.3 Definitions

Family: The definition of family is awkward and does not acknowledge the fundamental, biological connection between members of a family. We honor and respect that not all individuals who receive support through the Office of Developmental Programs have had positive or healthy relationships with their family members, however, we do not believe that the core definition of family should be altered for all people based on the unfortunate experiences of a few. Amending the definition to allow for an individual to identify those they consider to be part of their chosen family unit is appropriate.

Consider the following definitions:

Any group of persons closely related by blood, as parents, children, uncles, aunts, and cousins and those persons the individual considers to be part of his core family unit.

A group of people related by blood or marriage and those persons the individual considers to be part of his core family unit.

A social group of parents, children, and sometimes grandparents, uncles, aunts, and others who are related and those persons the individual considers to be part of his core family unit.

Natural Support: The definition of natural support should be expanded to read:

The personal associations and relationships typically developed in the community that enhance the quality of life for individuals. Natural supports may include family members, friends, neighbors, and others in the community or organizations that serve the general public who provide voluntary support to help an individual achieve agreed upon outcomes through the ISP development process.

Additionally, natural supports must be selected by the individual and should not be assumed. Natural supports supplement, but should not be used as rationale to deny needed paid services.

Add: Definition of volunteer, human rights, civil rights

6100.43 Regulatory waiver.

We agree that waiving the individual rights and positive intervention sections of the regulations should not be permitted.

6100.44 Innovation project

We support and encourage innovation and creativity in designing alternative and effective means to support individuals. Individuals must be informed of the innovation project and may not be required to participate in order to receive needed support. Participation in any approved innovation project should be optional.

6100.45 Quality Management

We support the inclusion of individual and family satisfaction surveys as well as informal comments in the quality management performance data which informs the quality plan. The quality management plan must measure employment and community participation outcomes. Quality management plans must be updated at least annually to assure continuous improvement strategies.

6100.46 Protective services.

We suggest that family be added to the list of those persons who are entitled to be informed of the rights to protection and be notified of abuse allegations and reports.

6100.47 Criminal history checks.

We have concerns regarding the requirement for criminal history checks for all household members. People have a right to share their lives with others, and we recommend that criminal checks only be required by those who are "paid" caregivers. We see under (d) that natural supports are excluded, however that statement assumes that anyone who is a member of the household (and not paid) is a natural support. This may or may not be true. A person may live in a home, but not provide any direct or indirect assistance or caregiving. (Same comment applies to **6100.48 Funding, hiring, retention and utilization. (a) (1)**)

Also, we suggest the addition of a definition of volunteer included in the definitions section of the regulations.

6100.51 Grievances.

We recommend the addition of:

The individual and their family must be provided information regarding the process to submit complaints and grievances to the administrative entity and the Department in addition to the process for grievance against the provider. Individuals must know and understand that they may have additional avenues for resolution beyond the provider level, especially if they are not satisfied with the provider dispute/grievance outcome.

Providers and Supports Coordinators must inform individuals and families regarding their rights to disagree and access mediation and fair hearing. The Supports Coordinator should be required to assist the individual and their family during the fair hearing process to assure they have information and support necessary to understand and participate in the proceedings.

6100.55 Reserved capacity.

We support the right of the individual to return to their home after leave. We would add that hospital or therapeutic leave cannot be used as a reason for discharge action by the provider.

6100.141-143 Training

We support the requirements for orientation and annual training for all employees and volunteers who support individuals. We recommend the addition of positive interventions to those topics listed. There must be rigorous attention paid to pre-enrollment provider orientation and training to ensure that all new providers have the skills needed to deliver high

quality service. Providers must demonstrate capacity, skills and knowledge in core areas necessary to support individuals appropriately. New providers should be offered substantial mentoring and support during the initial year of offering services and supports. Training should include emphasis on the principles of Everyday Lives and the importance of employment, as well as training around specific diagnosis, like autism, when the provider supports individuals with those needs. We also recommend that providers be required to offer training for individuals and families they support on person centered practices, including respecting rights, facilitating community integration, honoring choice and supporting individuals in maintaining relationships.

The training should be delivered face to face as much as possible, reflect best practices in the field, and require evidence of learning skills or concepts.

We support the exclusion of natural supports from this requirement, however, training for natural supports and the broader community should be available upon request.

6100.181-186 Individual rights

We fully support all the rights identified in this section and believe they must be supported at all times to exercise and enjoy their rights.

We recommend the addition of the following statements:

- An individual may not be deprived of their human and civil rights.
- An individual has the right to communication and understanding; including the right to be supported by people who speak their native language, and those supporters must be trained and fluent in their communication systems or alternative communication devices.
- An individual has the right to pursue and engage in relationships with others, including romantic relationships.
- An individual has the right to marry the person they choose.
- An individual has the right to have children and be supported in their role as a parent.
- An individual has the right to seek employment and income to support themselves.

Also, please add to the definition of terms in section 6100.3.

Human Rights – suggested wording:

The basic rights and freedoms to which all humans are considered to be entitled, often held to include the rights to life, liberty, pursuit of happiness, equality, and a fair trial, freedom from slavery and torture, and freedom of thought and expression.

Civil Rights – suggested wording:

Civil rights have the protection of the US Constitution and civil right is an enforceable right or privilege, which if interfered with by another gives rise to an action for injury. Civil rights include freedom of speech, press, and assembly; the right to vote; freedom from involuntary servitude; and the right to equality in public places.

6100.221 Person-Centered Support Plan

We support the name change from Individual Support Plan to Person-Centered Plan. We support one plan for each person, and the plan must meet all the criteria outlined by the HCBS Final Rule. We encourage ODP to develop a comprehensive training plan to assure that all stakeholders, including families and self-advocates, understand the principles of Person-Centered Planning.

This section should include the requirement that the plan be updated at least annually and at the request of any of the PSP team members. Assessments used to develop plans must be current and relevant.

The Plan should be written and spoken in language understandable by the person (their native language), and their family and team. Alternative translations should be required to assure the person understands the document. Versions may be video, picture or audiotape if necessary.

(Title VI Civil Rights and Executive Order 13166)

6100.223 Content of the PSP

Content must reflect what is important to the individual, including their preferences regarding where they live, with whom they live, their relationships, and personal goals. Therefore these should be added to the list in this section.

We suggest you move employment up to a higher position on the list since it is a priority in the system and evidence shows it have a tremendous impact on outcomes for people.

We are concerned that (7) Natural Supports may not apply to all individuals. Individuals may not have people in their lives who support them, therefore, this should not be mandatory.

When Natural Supports are available, the person must be afforded the option whether to choose those supports, as they have the right to decide who and how they are supported. A person must not be forced to use Natural Supports in lieu of paid services against their wishes. Additionally, the people offering natural supports must be willing and able to provide the needed services – and the planning team must document their commitment to do so.

Expand (9) regarding communication to require information regarding how the individual will be supported by people who speak their native language, and staff must be trained and fluent in their communication systems or alternative communication devices.

We have some concerns around (14) Modification of individual rights as necessary to mitigate risks, if applicable. We do not support the modification of individual rights by the PSP team without oversight by the rights committee and only under very specific conditions or situations. Circumstances where it may be necessary to modify rights must be approved by the rights team when clear evidence is presented to document that all possible services and alternatives to protect health and safety are exhausted before resorting to the loss of human, civil and individual rights.

Please delete (17) Excluded, unnecessary or inappropriate supports. We do not see the need to require this in each PSP.

6100.261 Access to the community

Access to the community is a right. Individuals must be supported to participate in “meaningful community activities”.

The individual must have the right to control their schedules and exercise autonomy, choice and control over where they go, with whom they go and when they go to community activities. Providers must honor their preferences and make sure that they have the freedom to optimize their options and choices each and every day.

6100.263 Education.

We recommend that individuals may access education for personal enrichment, and not just for employment outcomes. Many adults in the course of their Everyday Lives seek education as part of their access to the broader community, to develop personal skills, to find friendships, and foster independence.

TRANSITION –

We recommend the title be changed to read “Provider Transfers or Discharge” because that is a more accurate description of the section.

6100.303 Reasons for a transfer or a change in a provider

We recommend the following language for this section read:

6100.303 Grounds for Provider Discharge

(a) The following are the only grounds for a change in a provider or a transfer of an individual against the individual's wishes:

(1) The individual is a danger to the individual's self or others, at the particular support location, even with the provision of supplemental supports and meeting the individual's needs would require a significant alteration of the provider's program or building.

(2) The individual's needs have changed, advanced or declined so that the individual's needs cannot be met by the provider, even with the provision of supplemental supports and meeting the individual's needs would require a significant alteration of the provider's program or building.

Also, please add the following provision:

The provider may not discharge an individual against their wishes due to absence from the program, due to hospitalization, illness, time away visiting family, taking vacations, or therapeutic leave days.

6100.304 Written Notice

Please include the family in all written notice of changes in services or programs, with the consent of the individual.

6100.341 Use of Positive Intervention

We recommend the use of "challenging behavior" instead of dangerous behavior. Individuals may need positive intervention for behaviors that may not necessary rise to the level of dangerous, but none the less need to be addressed through positive supports.

6100.344 Permitted Interventions

We are confused by the language of manual restraint versus physical protective restraint. Individuals should only be protected through a physical protective restraint in the most severe dangerous situations, and only for a short time. A manual restraint should be defined as a hold that lasts more than 30 seconds with no restraint lasting more than 15 minutes in a 2 hour period.

We have serious concerns that individuals will be physically restrained by staff who are not qualified or trained to do so properly or when circumstances do not warrant restraint. We recommend that all staff must demonstrate competency to be considered 'trained'.

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

End the sentence in section B after the word damages, and eliminate 1-3 that follow.

6100.401 Types of incidents and timelines for reporting

In all sections that require notification, we ask that the family be added to receive notification of incidents. Additionally, the individual and family should be notified without having to request the report.

6100.441 Request for and approval of changes.

We support the inclusion of notification to the individual when the provider is requesting a change to the number of people living in a licensed location, however, we would like the family to be notified as well. The regulations are silent around the criteria that will be used to decide whether a request will be approved. How are the rights of the individuals living there and their preferences honored? They should be permitted to weigh in with the Department prior to a decision.

6100.446 Facility characteristics relating to size of facility

The Final Rule offers Pennsylvania the opportunity to truly transform our system. ALL settings must be held to meet the criteria of the Final Rule by March 2019. We are hopeful that compliance with the new regulations will provide the impetus for real change. People with disabilities deserve the opportunity to fully engage and participate in the broad community. The providers must be ready and willing to modernize and innovate in order to make real lives in the community available to all the people who need support. Individuals and their families need options and choices, support to realize their full potential, and access to the real community. Young people especially need to transition from education into the real world – not facility-based care. Individuals and families need to understand the full range of opportunities out there, be provided training and mentoring to understand how real person centered services can support individual goals, and learn from their peers about the possibilities. We need creativity, opportunity, and flexibility in the system and a provider network must be there to inspire and support, not segregate and isolate.

We believe that large, congregate settings that only serve people with intellectual disabilities will continue to segregate individuals from the broader community; therefore, those settings need to be phased out in a purposeful manner.

We support the regulation language which will limit group homes to 4 people – we believe all homes should meet this criteria, no exceptions.

We support the proposed limit on NEW day services to 15 people per setting, however we have concerns that large settings that support 100s of people may be isolating. While we appreciate the difficulty of downsizing those day facilities within the 5 year transition timeframe, we recommend:

- Annual decreases in the number of people served in those settings,
- Prohibition on new admissions to those settings.

We ask that ODP require the providers whose settings currently exceed the new size requirements be examined under heightened scrutiny and ODP should build compliance with the Final Rule into the provider contracts. The providers should be required to outline a specific plan, by 2019, for reducing their size and changing their business model. This plan should be a written document, submitted to ODP for approval, which will describe the actions they will take to downsize and reform their business practices to meet the new standards.

Beginning with this class of graduates, we need employment, volunteering and other opportunities in the community and we need to begin "right-sizing" the system now. Self-advocates and families must be able to teach and mentor people coming into the service system and their families what options are available for them to live real self-determined lives. If we don't start with the graduates now, we will have endless years of fighting about the closure and downsizing of these large day and workshop settings. We need a starting point.

We need to assure everyone has a meaningful life. To that end, let us work together, with these new regulations supporting us, to create a system that is person, not program driven. Pennsylvania can again provide the insight and leadership required to do this right for every person and family. We are the starting point and the time is now.

6100.463 Storage and disposal of medications

There needs to be provisions for assistance to individuals who require over the counter, non-prescription medications. This section appears to only apply to prescriptions, and is silent on administration of other medications as needed.

Technology and supports such as medication dispensers increase independence for individuals, and therefore regulations must allow exceptions for those individuals to some of the provisions of the medication sections.

General Payment Provisions:

At this time, it is difficult to offer specific input into the proposed payment methods. We recognize that individuals are entitled to have all their health and safety needs met, and therefore services must be funded adequately to meet their needs. Direct care staff need skills and qualifications to properly support people, especially those with high level of needs. The Department should invest in quality direct care staff. We need as system that is smart and efficient, while providing high quality, inclusive care in the community. We must have payment policies that enable support to be maintained for those with extensive support needs, including complex medical needs and behavior support needs.

We are unsure why the autism waiver rates need to be separate and apart from the services provided through the PFDS and Consolidated waivers. Rates should be consistent across programs, eliminate barriers to growing the provider network, and assure quality services for all.

We must also recognize that there are tens of thousands of individuals and families who are left out, languishing on waiting lists or interest lists and struggling each and every day. We have an obligation as a community to help as many people as possible, and be open to new and innovative ways to better support people.