3160

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Sent: Monday, October 15, 2018 11:08 AM
To: IRRC; irrc@pa.gov
Cc: 'Ahrens, Kristin'
Subject: IRRC Comments Department of Human Services Regulation #14-540: Home and Community-Based Supports and Licensing IRRC Number: 3160

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RE: Department of Human Services Regulation #14-540: Home and Community-Based Supports and Licensing IRRC Number: 3160

I would like to begin my comments by thanking the committee for the opportunity to submit them on these very important regulations which are being considered. I anticipate that the regulations of the Office of Developmental Program's licensing and home and community-based services, if approved, will be with us for a very long time. I appreciate the time that has been spent in meetings and getting comments from various stakeholder groups. I understand clearly that these regulations are intended to protect the health and safety of the individuals serviced by the various ODP programs. While they offer dramatic improvements over the existing 5100 regulations, which were implemented without IRRC involvement or agreement, they fall short of fulfilling the necessary steps to assure health and safety. My name is Ruth Landsman and I speak to you today wearing three hats. I am the parent of a young man receiving waiver services in unlicensed settings, I am the guardian of a young lady receiving licensed residential services, and I am an advocate who on average speaks to more than 500 families through the year in addition to email and listserv contacts where concerns and complaints are shared by families. While I understand the system's desire not to overburden providers, many more protections and management/accountability features are needed in these regulations to truly protect the health and safety of waiver participants which should be the primary focus.

INCIDENT MANAGEMENT

The broadening of areas where investigations are necessary in the incident management system is an improvement. The addition of individual to individual abuse as a category of incident now requiring investigation should help to improve appropriate levels of supervision contained in individual ISPs as this data is reviewed on a regular basis. The elimination specifically of emergency room visits will be a detriment and will lead to misunderstanding on the part of providers and possibly violations of the assurances provided to CMS for the waivers themselves. While these regulations indicate incident reports must be filed for any injury requiring more than first aid, by removing emergency room visits, it may mislead the agencies and staff required to report such incidents. Further, in some areas of the state, urgent care offices are frequently used before emergency rooms and their usage needs to be tracked as well. The gathering of the incident information in all areas covered by the regulations are designed to find trends and lead to better training and avoidance

of similar situations in the future. For this data to be useful it must be reviewed more frequently than quarterly, as the regulations suggest. I would strongly recommend monthly review of incident reports within each agency with quarterly review of all incident reports by the administrative entities and the office of developmental programs. In the past year there have been nearly 2500 emergency room visits in Philadelphia County alone. One need look no further than the horrendous situations that occurred at Blossom in Philadelphia in the latter part of last year to underscore the failure of the state and the administrative entity to oversee and hold accountable and improve the circumstances residents were encountering to view the total failure of accountability and assurances of health and safety of individuals served by this provider. Unfortunately, there are many potential similar situations likely to occur (with hopefully less disastrous outcomes) due to the lack of accountability efforts by the state. These regulations do not in any way address this serious accountability issue and they must!

MONITORING

With the self-assessments done by providers and the extraordinary lead time in setting up monitoring visits by support coordinators, licensing visits, and many providers who restrict families and guardians from receiving real time information, the providers are able to put on a "show" when visits take place. The focus frequently is on paperwork being completed accurately rather than care and support being provided adequately to the individuals served by the program. Although ODP has issued documentation requirements for building purposes, I have seen examples of daily notes, checklists, and tally sheets which do not in any way reflect what is actually occurring in some residential programs. Although there are house managers and assistant directors and support specialists in place within the agencies, the notes which are provided month after month document activities being completed in ways that are physically impossible and do not reflect the actual activities which are being completed. I could give specific examples of records if the committee would want to see/review them. Supervisory personnel frequently do not have the background or the training to realize the implications of the documentation they are sharing when pushed to do so. When visiting, families and or guardians are accused of conducting an inquisition when simple questions are asked of direct care staff. Many families and guardians have been directed to communicate only with supervisory staff and not with direct support professionals who are with our family members or charges while we visit. We are the eyes and ears not paid by the system to protect itself. These regulations put blinders and handcuffs on us!

PARENT/GUARDIAN INVOLVEMENT

The regulations, as they are being presented today, will leave up to the individuals with disabilities whether or not their parents or guardians participate in planning meetings and monitoring of service delivery. With some relatively rare exceptions, parents have the best interest of their children whether minors or adults at heart. Guardians appointed by orphan's courts in the various commonwealth counties have a legal responsibility to be involved and oversee the care of the individuals for whom they have accepted responsibility. By definition a guardian is a person who is entrusted by law with the care of the person or property or both of another as a minor or someone legally incapable to manage is or her affairs. This process is tedious and conducted in a conflict-free way. While some individuals in the system are able to speak clearly using typical language modalities or assistive devices, many are nonverbal and dependent on the knowledge and understanding of family members and guardians to interpret their desires and responses to questions. In all of these cases, there is a strong possibility of manipulation, whether intentional or not, which could allow providers to make decisions seem like they are coming from the individual but are really based on the convenience of the provider. The involvement of family members and/or guardians could help to assure individuals needs and choices are being met and honored without regard to cost factors. Without the support of family members

and/or guardians, when available, this vulnerable population may be talked into circumstances they would not choose with full and proper guidance. I do not believe that the regulations can supersede a guardianship order by orphan's court, yet the regulations seek to do so.

TRAINING

The issue of training required for direct care staff, supervisory staff, administrative staff, and executive directors appears to be inadequate given the training requirements contained in the various waivers. While I understand that the suggested 24 hours per year is a minimum, it does not seem adequate enough given the 40 hour training required to do community participation and supported employment. The 12 hours of training for executive directors does not seem to give them enough of the basis to oversee all of the programs they administer adequately. Without the executive directors of agencies being able to understand fiscally and programmatically, as well as implement the direct service programs their agencies offer, they must depend too much on their supervisors. This removes them from the line of responsibility to oversee their organization fully as is their responsibility. Just recently ODP began requiring 5 years of residential experience for any new executive directors (probably due to Blossom situation). To not require that executive directors receive ongoing training at least at the level of line staff what skills and experience they come in with will not keep up with changes in the system. In reading the comments and ODP responses to previous versions of these regulations, the theme that the department used as a justification for the amount of training they were requiring repeatedly indicated that the rates created for the fee schedule took into account this level of training. With the focus on community integration, and Everyday Lives, it is critical that every staff person who has any contact in any way with participants have the training necessary to offer support to staff and participants alike as the need may arise. Without adequate training for everybody working with individuals with disabilities covered by these regulations that is simply not possible. An example that I can give was a situation where a support specialist ordered equipment that did not meet the specific needs of the individual because they didn't have the background and understanding to read the specifications about what they were ordering to understand whether or not it would do what was needed in the situation for which they were ordering it. It may still not seem like much but this caused a six month delay and three orders and cancellations before the individual got what was needed to do "the job". In the end, the family placed the order, had insurance cover the device, and got it delivered to the residence within one week from taking over the process. Just getting the agency staff to acknowledge that they needed this assistance, which would and could have been provided much sooner, was a major task!

Due to cost of face to face trainings and duplicate staffing to serve individuals while regular staff is being trained has already led to a number of providers doing mandatory trainings via computer. While on the surface this appears to be a benefit, they further instruct their staff that they can complete the trainings while they are working during their regular duties. When staff are with participants their focus should be on meeting the needs of the participants not on completing training activities unless the participants are involved in the trainings themselves. I had an opportunity to witness a recertification for medication training of a staff person recently. As the house manager was observing the staff person in preparing medication dosages, she talked the staff person through step by step what they should be doing. At the end of the observation the house manager told the staff person (who they had given each step-by-step direction) that they were recertified and congratulated them! At a different agency in another situation, a staff person who made a single medication administration error was not allowed to give medications even with supervision until they had again completed the entire medication certification course again. This variation from agency to agency is not at all uncommon and due to the lack of required documentation or oversight by administrative entities and ODP, these various situations could cause serious detriment to the program participants.

TRANSPARENCY

ODP has spoken about report cards grading individual providers based on incident reports, staff backgrounds and training, consumer satisfaction, family satisfaction, cost-effectiveness, administrative policies and procedures, etc. After years of these discussions, the transparency simply does not exist! While discharges have been limited in these new regulations, without the report card information it is difficult, if not impossible, for families and individuals to choose other service options or providers. These regulations should include a process to collect, organize, and share information about all of the provider agencies in the system. As new agencies are created, there should be a probation period during which they are monitored by the administrative entity and ODP on a quarterly basis to be sure that they are complying with and understand all of the requirements to which they agreed and committed. There are a number of new agencies popping up that go through the process and become licensed and are not followed carefully enough to assure the quality of their services. This has led to a number of people being harmed because of misunderstanding or failure to meet all of the commitments entailed in being a licensed agency.

DECISION MAKING/DOCUMENTATION

Several meetings were held with legislators, family representatives, and advocates leading up to the IRRC's consideration of these regulations. There was an attempt by a legislator to get ODP to withdraw and resubmit the regulations with modifications this year which was refused. The acting deputy secretary also refused to address any of these and other issues that have been brought to her attention as grave concerns on the part of family members and advocates. There is strong documentation (listed in comments from a colleague) such as newspaper articles, and OIG report, CMS documents, etc. I hope that the commission will review much of that documentation in making your final decision. In considering these regulations it is important to highlight that one of the rallying cries for community living rather than institutional placement, was people would be safer and families and residents would have more involvement and support. I ask that you not accept these regulations as they have been submitted to you at this time but, if amended to address these serious concerns, place them on the IRRC schedule in an expedited fashion before the end of the year..

Submitted by Ruth Landsman

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