OPRA Comments on Draft Behavior Support Rule

The Ohio Provider Resource Association (OPRA) is a statewide association of providers of services to individuals with developmental disabilities. OPRA is a leader in efforts to collaboratively build a statewide service system that meets the needs of Ohioans with developmental disabilities. Currently, OPRA's membership consists of more than 150 organizations, both for-profit and not-for-profit, providing services to more than 15,000 Ohioans with developmental disabilities. Our mission is to support and provide advocacy for community-based service providers to ensure the availability of programs, services and funding adequate to support and assist individuals with developmental disabilities as they strive to achieve a life of increasing independence, productivity, and integration.

Thank you for sharing the draft Behavior Support Rule. We appreciate the opportunity to comment and want to formally recognize the amount of work that has been devoted to this during the past several months. Below is a summary of responses from the OPRA membership, which have been categorized by issue. I have also included in a separate attachment, comments and feedback from four clinical psychologists who work in residential settings in different areas of the state. Their feedback is primarily devoted to the clinical aspects of the rule, but includes some concerns about the impact on the ICF programs and services. OPRA concurs with these comments.

(H)(12) Restriction of an individual's rights: We received numerous comments on this provision. Examples were provided wherein the target behavior did not pose an "immediate risk of physical, emotional, or psychological harm to self or others" but clearly interfered with the individual's growth and development, attainment of personally valued outcomes, legal status and/or integration into the community. Medicaid services are required to ensure health and welfare. We need to be mindful of this as we move forward. As discussed, we will share some specific examples at the next stakeholder meeting. We recommend that that an additional level of restrictive techniques be developed that addresses these situations and that implementation be contingent upon Human Rights prior authorization and HRC/Behavior Support Committee oversight.

(M)(2)(a)-(d) Human rights and ethical oversight committees: As we have stated in previous comments, the HRC membership requirements as listed are simply not attainable. Members consistently report great difficulty in meeting the current requirements, which are considerably less onerous than those listed in the draft. We recommend keeping the HRC structure as it currently exists. Concerns about possible HIPAA violations were also expressed, especially around individuals who live and/or work together. We request the department's legal opinion on HIPPA compliance in HRC review and oversight.

(M)(6)(a)-(j) HRC department approved training: Again, there were numerous comments on this provision. The language does not specify the length of training, which could be extremely problematic once DODD develops parameters. As the rule currently exists, it is difficult enough to find volunteers for HRC's. Adding additional time for a volunteer seems counter-productive to the establishment of full and functioning committees as it will make it that much harder to recruit and retain members. The training requirements for HRC members appears to be more stringent the requirements for plan authors.

(O) Analysis of risk reduction strategies: This imposes yet another set of requirements on volunteers and adds yet another regulatory based process for ICF's. We agree that individual plans need HRC oversight but disagree that this over-arching analysis will benefit the system or those receiving services.

(I)(2)(a) Medication for behavior control: This provision appears to minimize the needs of individuals who have been dually diagnosed and who may require medication for reasons other than preventing incidents that pose an immediate risk of harm. It is important that the service system meet the needs of individuals served, including mental health needs. All treatment options (therapies, support groups, medication) should be recognized and made available to individuals with DD.

Time Out: "Child" needs to be defined. Is a child anyone who is not yet 22? Someone who is still in high school? Or under 18 as it is for individuals without developmental disabilities? Time out is specifically addressed in the ICF Medicaid interpretive guidelines and regulated by ODH and CMS. The complete elimination of time out will prohibit the use of a strategy that has proven successful for a *very small* number of individuals. We believe that it should be used in only the most difficult of circumstances when other measures have proven unsuccessful and that it should be very closely monitored. We would recommend that additional oversight provisions be developed rather than eliminating it completely. We can provide specific examples if needed.

Additional DODD ICF reporting and oversight: As noted above, ICF's are currently regulated by ODH via CMS regulations. We oppose any additional reporting, oversight or conflicting regulatory provisions that are contained in the draft rule.

Again, thank you for the opportunity to comment. We look forward to working with you to ensure that quality supports can be provided while lessening the administrative burdens and reducing and/or maintaining the current costs of behavior support planning and implementation.

Anita Allen

From:	Chip Kobe <CKobe@Heinzerling.org>
Sent:	Wednesday, January 22, 2014 1:09 PM
To:	Anita Allen
Cc:	Chris Rafeld; Colleen Channel; Rachel Hayes; Michael Marriott; Lakeisha Davenport; Sandys NKrumah; Betsy Cleland
Subject:	Behavior Support Rule feedback

Hi Ms. Allen:

Chris Rafeld, Administrator at The Heinzerling Foundation asked that I send my comments on the proposed Behavior Support Rule directly to you.

My perspective comes from experience at both the county board level and with several ICF/IDD organizations. The following points reflect concerns in managing 'cross system' regulatory elements for ICF/IDD providers. All providers of DD services recognize the considerable demands of managing the behavioral support and human rights review processes. However, ICF/IDD providers generally have a higher level of regulatory demands for all aspects of programming and facility operations. Please let me know if you have questions regarding the points included here.

- The current Ohio DODD Behavior Support Rule excludes ICF/IDD programs. This exclusion is presumably due to past concerns with cross-system regulatory issues. As these issues still remain, the inclusion of ICF/IDD providers into the proposed rule appears arbitrary and unnecessary. This is because all aspects of the behavior support and associated human rights review processes for ICF/IDD programs are comprehensive and clearly outlined in existing CMS regulations.

- Inclusion of the ICF/IDD into the Ohio DODD Behavior Support Rule would essentially create an additional set of rules, along with new terminology and major procedural changes. Because many of the proposed changes may create inconsistency with existing CMS regulations, requiring ICF/IDD inclusion would represent a form of dual regulation that is unnecessary and burdensome to the operations of ICF/IDD providers.

- Current Ohio DODD residential facility licensure rules already provide an existing structure for DODD oversight regarding behavior support and human rights review processes of ICF/IDD providers. The proposed change in the Behavior Support Rule by the Ohio DODD creates an additional and overlapping regulatory structure for licensed ICF/IDD residential facilities.

- The proposed Ohio DODD Behavior Support rule incorporates changes in basic structure and terminology that is inconsistent with *both* existing CMS and Ohio DODD facility licensure rules. Behavior support and human rights review processes in both CMS and DODD licensure rules at this time are clear.

- The proposed changes to the DODD Behavior Support Rule use new terms and concepts, such 'risk reduction strategies' and 'risk reduction assessment' that are not part of CMS regulations or Ohio DODD licensure rules. Integrating these types of new terms and concepts will make increasingly more difficult for ICF/IDD providers to manage the behavior support and human review process. Additionally, there will likely be unforeseeable and unintended consequences from this type of change.

- ICF/IDD providers would likely experience a substantial adverse operational and business impact by inclusion into the Ohio DODD Behavior Support Rule. This type of arbitrary inclusion and rule change by Ohio DODD appears contrary to Ohio's Common Sense Initiative pertaining to rules that are unnecessary and burdensome to ones' overall business operations.

- Because of the concerns noted, there appears to be an economic impact to ICF/IDD organizations by the proposed rule. Even some of the small changes (e.g., the composition of the HRC, addition training for HRC members, additional Ohio DODD reporting requirements) will impact the operations of an already difficult behavior support and human rights review process for ICF/IDD providers.

Frank 'Chip' Kobe, Ph.D., Psychologist, Behavior Consultant

January 29, 2014
5010 Mayfield Road
Lyndhurst, Oh. 44124

Anita Allen
OPRA
1152 Goodale Boulevard
Columbus Grandview Heights), Oh 43212

I am writing to provide some comments on the DODD draft behavior support rule. As you probably know, I am a clinical psychologist with more than 30 years of service to the developmental disabilities community. I was the Chief Clinical Office at the Cuyahoga County Board of Developmental Disabilities for approximately 20 years and I was a member of the DODD Behavior Support Advisory Committee for approximately 10 years. I have continued to provide a variety of services to the developmental disabilities community since my departure from the Cuyahoga County Board of DD in 2005.

The proposed rule has many positive features and I appreciate the efforts of the committee to promote positive practices and a respect for human rights. I do have some concerns, however, about the prohibition in the draft rule against the use of rights restrictions in situations where a person's behavior does not create an immediate risk to health and safety and I would like to convey my concerns via this letter. I would like to share my rationale, some case examples to illustrate my concerns, and a proposed solution.

I. Rationale

There are a number of occasions where individuals with DD engage in maladaptive behavior that does not pose an imminent threat to health and safety, but which does interfere with the person's growth and development. Whether or not the person is legally competent, these maladaptive behaviors rarely represent informed choices by the individual. These individuals often have relatively well developed cognitive skills, typically presenting with mild intellectual disability or borderline intellectual functioning. In addition, they frequently have dual diagnoses. The maladaptive behaviors of concern may involve the use or misuse of technology, at least at a surface level.

The rationale for restricting the person's rights often involves creating conditions to help the person learn from experience, and given the repetitive and generally compulsive nature of these maladaptive patterns, it is rarely sufficient to educate the person or to meet the person's underlying needs, though these measures are of course be necessary of not sufficient.

It is recognized that rights restrictions can easily be abused, and for this reason they should be subjected to the highest level of oversight, meaning that they should require prior authorization from Behavior Support/Human Rights Committees. Among other things, these committees should be presented with compelling rationales for the use of rights restrictions which make a plausible case that the issue indeed does interfere with the person's growth and development and that a rights restriction is not being recommended solely or primarily for staff convenience.

The following examples should illustrate the issues.

II. Examples

#1—This person is in his 20's and has borderline intellectual functioning and has repeatedly called 911 for issues that invariably did not prove to be medically necessary. The calling of 911 probably served several purposes, including creating drama and excitement, eliciting nurturance from medi-

cal personnel, and misunderstanding the appropriate use of 911. The net effect of this issue was to create much instability in the person's life and it also helped the individual avoid dealing with underlying issues that were unpleasant, such as rejection by his family. A behavior support plan was developed that involved restricting (but not entirely eliminating) the person's access to a telephone, along with positive measures such as helping the person learn how to use 911 appropriately, learning to cope with anxiety, and obtaining counseling for emotional issues. The plan also clearly defined how the person could regain unrestricted access to the telephone.

The plan was highly successful, and after two years the inappropriate calls to 911 ceased entirely (they were occurring on a weekly basis when the plan was started). This plan has now been discontinued because the person no longer needs the plan or the rights restriction. The team believes that the rights restriction was a key element in the success of the plan, although by no means the only element.

#2—This person in in her 20's and has mild intellectual disability and Asperger's. She has a great deal of technological savvy involving the use of the internet and cell phone. She has had access to cell phones and landlines and has repeatedly called particular individuals (for example ten times within one hour) despite the request from the receiving party to desist. It is likely that the person engages in this behavior because of difficulties in forming social relationships and to reduce anxiety, but the net effect is that the repeated calling alienates others and adds to the person's sense of isolation. Many steps have been taken to address the underlying problem, including working on social skills, providing education about the appropriate use of technology, and helping the person manage anxiety, but the team has recommended a telephone restriction that limits but does not entirely restrict the person's access to telephone technology.

This situation is still ongoing. The team believes that the benefits of this rights restriction outweighs the risk, because the person is unable to stop herself on her own and the repeated calls increase her loneliness and social isolation and interferes with the learning of new skills.

III. Proposed solution

The new draft rule could address this issue by permitting the application of rights restrictions in situations such as I have described, where the person's behavior does not pose a risk to health and safety but does interfere with growth and development or the attainment of personally valued outcomes. I believe that this would require the creation of two levels of restrictive techniques in the rule, the first of which deals with rights restrictions that do not create high risk, whereas the second level does deal with restrictive techniques applied to situations where there is an imminent risk to health and safety. Of course, both levels of restrictive techniques should require prior authorization and the highest level of oversight possible.

I hope these suggestions are helpful and please let me know if you have questions.

Sincerely,

Stephan A. Schwartz

Stephan A. Schwartz, Ph.D.
Psychologist

January 30, 2014
Ohio Provider Resource Association
c/o Anita Allen
1152 Goodale Blvd.
Columbus, Ohio 43212

Dear Anita;

I wanted to comment on the Behavior Support Rule. Certainly using positive strategies, protecting the rights of clients, promoting personal growth, and ensuring health and welfare are essential to people we are serving. There were a few items in the rule that may need closer examination.

The first is the make-up of the Human Rights Committee. Having clients on the team is a wonderful idea. The challenge could be, for some providers, finding two clients who have the capability to understand everything that is being discussed. Also the possibility of confidentiality being compromised, especially if the clients being reviewed by the Human Rights committee live or work with the clients serving on the Human Rights Team. The other concern is the Human Rights Committee is made up of volunteers, hopefully with the new training requirements we are not making it more difficult to have people volunteer in our field.

In regards to H (12) and Prohibition of rights restrictions absent an immediate risk of harm (i.e. restriction smoking), we must make certain we do not infringe upon other's rights (those who do not smoke, living in the household). This is only one example, but sometimes by well-intentioned actions of protecting the rights of one client, we infringe upon the rights of another. Our attempts to help guide individuals to live a healthier life hopefully will not be hampered by this clause.

In regards to F (1) (b) people who have years of experience developing behavior support plans or risk reduction strategies (for individuals with a violent history or sexually aggressive behavior) does not necessarily make them competent in doing so. It seems there is often a challenge for good positive behavioral support plans being written and well intentioned authors do not always hold the tools to indeed create a successful, positive plan. It ends up being a disservice to the individuals we serve.

I hope, in general in regards to this rule, we are not creating additional paperwork and documentation that takes away time from interaction between caregivers and individuals being served. It appears that as we progress in this field the level of paperwork progresses at a much faster

pace, diminishing our foundational efforts to truly help the individuals we serve obtain positive outcomes. In other words for a system whose goal is outcome-based, we certainly have the propensity to bog it down with a heavy load of documentation.

Thank you for your time and consideration.

Sincerely,

Roger Fortener, Ph.D.
Assoc. Executive. Director
Psychologist

Hi Anita,
I have reviewed the latest behavior support rule revision and have a few areas of concern.

1. Little consideration to dual diagnosis and the role of mental health in needing behavior support.
2. Limiting use of restrictions that can put the individual and/or public in danger.
3. Training criteria for human rights committee members vs program authors.

Thanks for listening
Joe

Concern #1
Over the years it has become increasingly recognized that individuals with developmental disabilities can have the same mental health issues as those without developmental disabilities (Dual Diagnosis). The proposed rule is a step back in time with mental health factors being minimized. It seems likely that many individuals need "behavior support" due to behavior issues that are closely linked to mental health issues. You have to go all the way to - E 5 b) iv – to find any mention of mental health issues.

Recommendation
In the philosophy section in could be mentioned that some problematic behavior may be related to the mental health needs of an individual and that it is important to meet their mental health needs. In doing so all treatment available to individuals without developmental disabilities who have mental health needs should be available to individuals who have a developmental disability and mental health needs. This includes medication, individual or group therapy/counseling, and support groups as needed.

Concern #2
At times restrictive measures are needed in risk reduction to "prevent" a situation of danger or harm from arising. Without these measures there is a greater risk of danger or harm. The proposed rule seems to look at situations where the harm or danger is "in process". This could be very damaging for individuals being supported and those around them. Consider the following restriction that are put in place before the danger arises in order to prevent dangerous situations:

- Person with history of arson – restriction of having matches and lighter
- Person with history of sexually offending vulnerable others – restrictions in where they live, access to children, monitoring of mail and possessions (receiving material that increase probability of offending),
- Person with history of violence with weapons – restricting access to weapons
- Person with history of severe SIB – restricting access to things used to harm self (i.e fork, knives, etc)
- Person with severe Pica – limiting access to materials that they are known to swallow which could be life threatening.
- Person without safety skills - limiting access to outside without proper clothing or supervision
- Person without safety skills – limiting access to cleaning materials that could be dangerous

Recommendation
The proposed rule treats all restrictions the same. However, restricting small metal items from a person who displays severe pica, in my view, is not at the same level as a restraint/escort/or response cost. The rule could recognize the differing levels of restriction. In particular, the use of the term "immediate

danger" as the criterion for use of the restrictive measure may be used for higher level of restriction (such as hands on procedur4es like escort or holds), but not the lesser. For example, the pica behavior may occur only 10% of the time that the person has the items, but this is still a danger in the long run. This consideration also needs to be given for the other "preventative" restrictive measures. I have worked with numerous pedophiles who are living in community settings. Many have been adjudicated "not competent to stand trial" so charges must legally be dropped, even though it is known they did the crime (no court ordered community controls). If they are in the mild range of intellectual disability the court cannot retain jurisdiction, so they go free. Nonetheless, they do pose a risk to society and the responsibility appears to be placed on the Dept of DD to keep the public safe. Restriction seems necessary. I don't think we want to go down the road of saying - keep them away from children but don't call it a restriction. It is a restriction, but a necessary restriction. The same can be said for a person with the history of arson. I know of someone with such a history living in a large apartment setting. If restrictions were not in place, many people's lives would be in danger.

Concern #3

There seems to be greater training requirements for the members of the human rights committee, than for program authors. The committee members must have documented training a 10 areas. Program authors do not have this training specification. It is assumed rather than specified. How does a program author get the 5 years of experience in writing if they cannot write the programs until they have 5 years. It appears that this assumes co-authorship, or supervised authorship, although it is not specified.