Institute on Public Policy
for People with Disabilities

# Institute Comments to Draft Rule 115
# 4/8/21

## Background

The Institute on Public Policy for People with Disabilities is the largest state association in Illinois devoted exclusively to people with intellectual and developmental disabilities (I/DD) and the community organizations that support them. Institute members collectively support 19,000+ people with I/DD in community settings and provide Independent Service Coordination (ISC) to 10,000+ people with I/DD. The comments that follow were drafted by a committee of Institute members with the full support of the Institute board. We submit these comments in the spirit of collaboration and interest in promoting consistent understanding and interpretation of Rule 115 by all stakeholder groups.

## Overarching

The opportunity to comment on and shape Rule 115 is a once-in-a-lifetime opportunity and was treated as such by the committee that informed the comments that follow. During the course of extended meetings, several thematic issues emerged in addition to the section-by-section comments that follow.

- Shortcomings in the proposed discharge process.
- As we state further in our section-specific comments, the language of the rule is aspirational and visionary, but not reflective of the rate structure associated with CILA service delivery.
- The Rule falls short of acknowledging the rights of all individuals living in a CILA setting in instances where 1 person is harming others.
- Rule 115 provisions have been subject to varying interpretations by surveying/ monitoring/oversight entities which vary by entity, provider, and individual circumstances. As such, we have submitted extensive comments regarding definitions to assure a universal and objective understanding. We expect that the subsequent auditing tool will also supply surveyors/monitors with standardized compliance metrics as well as structures for ratings compliance based on statistically significant measures.
- Every section of the rule should be subject to the question – "how is this measured?". If this question cannot be readily and consistently answered, the section should be revised to assure a universal, objective, and measurable standard for evaluating compliance.
- We advise separating the I/DD and Mental Health CILA provisions for ease of understanding and application. We request that DDD collaborates with DMH to put forth a unified message regarding Mental Health CILA requirements, as providers have received varying guidance regarding a need to adhere to Rule 115.

## Subpart A General Provisions

**Section 115.100 Purpose (pg. 20)**

a) Insert the acronym CILA following Community Integrated Living Arrangement as it is the first time it appears in the document.
b) Define "meaningful and valued lives" as this is experienced differently by all people.
c) –
d) Provide further detail regarding the contents of "provider agreements and accompanying attachments"; if the Rule is the source document for providers to follow in meeting state requirements it should contain clear reference.
e) Similar to above comment (and to be made again), we advise that references in 1 – 4 be embedded in Rule 115 rather than referenced to promote proper compliance.
    1) CFR 441.30c) is missing a 1 in front of the (c)
f) Understanding that DD and MH CILA services are separately funded, language in this section doesn't acknowledge that many (most?) people with I/DD in CILA settings have a dual I/DD and MH diagnosis. We suggest adding "primary" to the DD and MI references in this section. We

further suggest consideration of separating the DD and MI direction in the Rule as is being done with references to HCBS and ICFDD requirements in Rule 119.

**Section 115.120 Definitions (pg. 22)**

Abuse

This section is explicitly titled "Definitions" yet does not contain actual definitions for key terms including Abuse. We advise including the full definition.

Accreditation

There's no logical explanation for defining and accepting accreditation for MI organizations but not for I/DD organizations; we advise applying the same definition and standards to both types of organizations.

Agency Supervision

This term is defined but the preceding original definition of "agency" is redacted, causing potential confusion regarding which agency (community provider or state agency) is being referenced.

Applicant

The definition states that a person or group of persons can apply for a CILA license; we are unclear that this is permissible?

Array of Services

The language used in this definition is subject to interpretation and could be used as a basis for potential neglect allegations against a provider if one's interpretation led to expectations the provider could not meet, e.g. a person may want to go into the community with 1:1 staff support on a daily basis to promote maximum independence but the provider agency is unable to meet that expectation due to staffing patterns. We advise the word "array" be removed and changed to CILA Services with the definition reflecting services the provider organization is paid to deliver. The term "and skill building" at the end of the definition makes no sense. Note last words of definition – "…not receiving HCBS and skill building" seems awkwardly expressed. What skills are referenced here? If this definition is to be fully implemented as written, does it mean that two persons who need 24-hour supports and now want to live together will be able to do so – and be funded accordingly? Are there any resource constraints?

Assigned Independent Receiver

Understanding IDHS' authority to revoke a CILA license, we're unclear why/how a circuit court would have the authority to appoint a receiver?

Authorized Agency Representative

Add "or designee" following the word "head".

Authorized Electronic Monitoring

Change "his or her" to "their" for consistency across the rule.

Aversive Procedures

It might be helpful to include a more contemporary definition – see the following position statement on aversive procedures (an AAIDD publication):

*Position Statement of AAIDD*

Some people who have an intellectual or developmental disability continue to be subjected to inhumane forms of aversive procedures as a means of behavior support. The American Association on Intellectual and Developmental Disabilities (AAIDD) condemns such practices and urges their immediate elimination. The aversive procedures to be eliminated have some or all of the following characteristics:

1. Obvious signs of physical pain experienced by the individual.
2. Potential or actual physical side effects, including tissue damage, physical illness, severe stress, and/or death.
3. Dehumanization of the individual, through means such as social degradation, social isolation, verbal abuse, techniques inappropriate for the individual's age, and treatment out of proportion to the target behavior. Such dehumanization is equally unacceptable whether or not an individual has a disability.

This statement is intended to articulate important values and principles and to challenge the field of developmental disabilities to promote research activities leading to identification, testing, implementation, and dissemination of non-aversive alternatives to address severe behavioral disorders. Specific regulations regarding research, clinical practice, or individuals in making professional judgments are the province of regulatory agencies, funders, and certifying bodies.

Eliminating inhumane aversive procedures is a reflection of a growing concern for reducing actions by professionals and others that compromise the lives of people with an intellectual or developmental disability and their families. Positive behavior supports not only should reduce problem behaviors that pose functional barriers to successful life, but also enhance those behaviors that lead to self-determination, independence, productivity, and lifelong learning. Relationships between providers and self-advocate should foster the empowerment of the person, enhance choice, and promote the integration of people with intellectual disability or other developmental disabilities into community settings.

Revised and amended on January 29, 2020.

Certification

Will BALC be changing its current process to provide site-specific documentation of certification?

Coercion

This appears to be a new definition in the rule; while agreeing that CILA participants should not be coerced, there are several possible scenarios that in the course of review could be interpreted as acts of coercion:

- A person doesn't want to attend CDS programming but there is no staff to stay home with them.
- A person doesn't want to take prescribed medications.
- A family mistreats staff/other residents in a CILA home and is barred from the premises.

It is recommended that in any definition of coercion that the context of such action is understood. For example, is it an act of coercion to prevent a person from harming themselves or others? A person walking into traffic? A person starting a fire, not allowing a person to leave their residence without a coat in below zero weather, when going out of doors?

It is recommended that the definition be reworked.

Community Integration

We have several comments/suggestions to this definition:

1. The definition pertains to the state's responsibility, not the CILA provider ("…the state must ensure…) and as such, should not be included in the rule.
2. The effort to comply with the settings rule is again acknowledged but the implications should also be recognized. To carry out this definition requires sufficient funding and resources. Providers should not be faulted for a lack of full compliance because of a lack of resources, whether by the DD Division, BALC, or OIG.
3. Define "full access" as this is ambiguous and subject to varying interpretations by BALC, BQM, OIG and guardians.
4. Change "living arrangement" to "home".
5. The definition should allow for people to participate in activities of their choosing, which may include disability-specific options that may be incredibly meaningful to the person.
6. What amount of time are people expected to spend outside of their home? If there is no guidance, there can be no unacceptable amount by BALC, BQM, OIG or guardians.
7. Remove "guardian" from the language regarding the type and amount of activities the person participates in as this is not duty of court-appointed guardians. Add "and within the person's financial means" following "greater community".
8. Change YMCA and YWCA references to "park district".
9. Change "spiritual" to "church, temple, mosque, synagogue or other places of worship" as these are much more understandable terms to people supported.
10. Remove "family" from the definition describing activities as many (most?) CILA participants have no family contact (as evidenced by OSG appointment) and are excluded from this description. Many CILA participants willingly and happily spend time in the community with others from their home and/or supported by their organization.

Continuous Supervision/Support
How is "care" distinguished from "Supervision/Support"?

Critical Incidents
The definition appears to be new language and the term "reasonable risk of harm" must be defined with examples of what is intended. We recommend that the components of CIRAS manual regarding incident categories be included here. Specific clarification must be provided regarding maladaptive behaviors which lead to police support, trips to the ER which do not lead to hospitalization, and instances where building fire alarms alert emergency services, initiating a "911" incident for multiple people.

Deemed Status
Explain the rationale for applying "Deemed Status" only to MH agencies and not I/DD organizations. It is recommended that "deemed status" be just as applicable to DD agencies as well as mental health agencies, as both are divisions of the Department of Human Services. DD agencies should enjoy the same opportunities as mental health agencies, especially as it pertains to matters of quality assurance. It is further noted that granting greater recognition to the accomplishments of accreditation would free survey staff to spend greater time with new or struggling agencies.

Developmental Disability
Explain the rational for changing age from 18 to 22 yet leaving at 18 for the Intellectual Disability definition. A more contemporary definition should be included. See AAIDD definition:

> *"Developmental Disability: A severe, chronic disability of an individual that: (a) is attributable to a mental or physical impairment or a combination of mental and physical impairment; (b) is manifested before the individual attains age 22; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in three or more of the following major life activities: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and (e) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic service, individualized supports, or other forms of assistance that are lifelong or of extended duration."*

Diagnosis
Include reference to the more contemporary understanding of disability reflected in the AAIDD 12th edition Intellectual Disability Definition, Diagnosis, Classification and Systems of Support. We advise using the more comprehensive and widely used ICD10 codes.

Direct Support Person
Use consistent terminology throughout rule and consider adopting the widely used Direct Support Professional title. Remove the term "habilitative care" as it is an outdated concept (see comments under "Habilitation" definition. Also, "higher-level employee" should be clarified to reflect a staff member who has supervisory responsibility for the work site employing DSPs.

Electronic Monitoring Device
Define room.

Employee
Remove "volunteer", as elsewhere the rule distinguishes volunteers from employees and by definition, an employee is paid.

Equivalency
We are unclear what is intended by this definition, particularly in light of disallowing "Deemed Status" for I/DD CILA providers; please provide examples.

Exploitation
This is a critical term that warrants full definition, not a reference.

Habilitation
We suggest the following languagea; "Habilitative services help a person keep, learn, or improve skills and functioning for daily living. In contrast, rehabilitative services help a person keep, get back, or improve skills and functioning for daily living that have been lost or impaired because a person was sick, hurt, or disabled. Habilitative and rehabilitative services can involve the same services, provided in the same setting, to address the same functional deficits and achieve the same outcomes; the difference is whether they involve learning something new or relearning something that has been lost or impaired." (AOTA, 2018) CILA services aren't intended (nor able) to "alleviate" a developmental disability. The examples of services rendered are not consistent with activities that would be carried out by DSPs, where the term "habilitative" is referenced and therefore should be removed.

Host Family
Either change the term to be inclusive of the setting or redefine as a family rather than a setting.

HFLA – Traditional Care Model
If going to use the term "care" it should be defined to assure a clear understanding of what is intended/expected by this term. Define caregiver – not defined elsewhere.

Imminent Risk
We're concerned that this definition imposes a standard of action that in reality, may not within a CILA provider's ability to execute. There are countless examples within the CILA system of patterns of actual (not immediate, threatened or impending) peer to peer mental and physical injury that after extended effort, cannot be resolved by the CILA provider yet discharge efforts are denied. This is a definition that also needs to be recrafted. It is recommended that providers participate in such an undertaking. It does not seem logical as presented. Why would a prudent person take *immediate* action based on preliminary determination? Also, if a term such as "mental injury" is to be used within the rule, it should be defined. Can mental injury be both and act and an omission?

Implementation Strategy
We advise changing "in conjunction with…" to with input from person/guardian based on their availability/interest as the current language requires involvement which in many cases is untenable.

Independence in Daily Living
We feel the definition and examples listed here are inaccurate and confusing.

- The definition states the person can care for themself without assistance, in which case they would not be in need of CILA services.
- CILA providers are not responsible for vocational development, outside or inside the living arrangement.
- The personal care examples could be better captured by referencing the 6 life areas included in the eligibility requirements.
- Remove the reference to citizenship.

Independent Monitor
The definition states "CILA" but later references a "CILA agency"; the definition is unclear if an individual CILA setting or an entire CILA agency is intended. Understanding IDHS' authority per the Rule to discontinue approval for the delivery of CILA services by an CILA provider, the definition includes actions and powers that would seem to require the provider organization's agreement/acceptance, which may or may not be provided.

ISC Definition
In the interest of advancing conflict of interest free case management, we advocate for people being able to choose their own ISC. There is also ambiguity in the second sentence, especially as it relates to the provider role.

Individuals
We advise changing to "person".

Intellectual Disability
We recommend using a more contemporary definition that does not rely solely on IQ level. See the AAIDD 12th edition (Jan 15, 2021) Intellectual Disability for guidance. Should not the age be 22, to be consistent with the umbrella definition of developmental disability?

Intermittent Supervision or Supports
Is this 24-hour or ICILA? Definition should include reference to remote supports. We're unclear on what a "paid neighbor" is?

Linkage
Our understanding of this term is that it is an ISC function in I/DD services; please clarify who is responsible for linkage and provide examples for further clarification. What does person to person contact mean? Linkage across the DD system involves much more than just the Personal Plan and Implementation Strategy.

Living arrangement
Can we consider replacing this term with "home" as in Home and Community Based Services? Him/her should be replaced by "their" for consistency. Our understanding of the HCBS Settings Rule does not supplant the person's decision with that of the guardian.

MHP
Define the term.

Mental Illness
Is the list of conditions here selective vs. exhaustive? The list does not include commonly seen conditions such Intermittent Explosive Disorder. Assuming there is a reference for this definition it should be provided. We are unclear on what constitutes "supportive treatment".

Natural Environment
The final word needs clarification (treatment).

Natural Supports

What is expected as evidence of an informal agreement and what is the provider role/responsibility relative to natural supports? It is suggested that this definition be strengthened; it seems to describe more of a sought-for service than an act of kindness. In fact, natural supports are often provided by family members. Natural supports are associations and relationships. Often these occur without an informed agreement sometimes because the person with a disability is unaware of the nature of the benefit being received. In many definitions of natural supports, one-time acts of courtesy are in fact included. See Inreach Study Guide: Natural Supports https://www.inreachnc.org/images/pdfs/naturalsupports.pdf

Neglect
Define maintenance. "Care" is used here but not defined in the Rule. This word has proven to have different understandings and expectations by bodies in a position to review provider services and needs to be explicitly and objectively defined here.

Plan of Correction
Our understanding of current practice is that a POC is necessary in response to low BALC and BQM scores following surveys not just violation.

Professional
Are DSPs included in this definition?

Provider
Define this term rather than reference to another definition.

Provider Controlled
"Home and Community Based Services" is used in lieu of CILA provider in this section but has not previously been defined.

Provider Support Team
The CILA rate methodology does not fund nursing participation on the "provider support team" and should be removed.

QIDP
Given the challenges in maintain an adequate QIDP workforce, we suggest consideration of an exception process to expand opportunities, as well as an Assistant QIDP option who would work under the supervision of a QIDP.

QMHP
Define

Relative
We find the definition too prescriptive as people listed under the definition may have no relationship with the person and many people define their family/relative in their own terms.

Relief
We advise that Relief staff in host home settings be a contractual arrangement between the host and the relief staff with payment provided by the agency. Many host home families are uncomfortable with agency personnel living in their homes for extended periods of time and prefer to make such arrangements themselves similar to employment of PSWs in HBS.

Respite
If this term is meant to address respite provided in a CILA setting, it should do so in the definition. If not, we're unclear what its purpose is in this section.

Restraint
Restraint and medical immobilization and separate procedures requiring different levels of authorization and approval; we advise they be 2 separate definitions. What does amelioration of physical disability mean? Where do CPI/Safety Care techniques that involve physical contact with the person fit relative to this definition?

Self Admin Meds
We advise that commonly available technology be available to people in CILA settings to assist in their independence in medication self-administration.

Site
Delete under continuous roof and consider each separate home/apartment as a CILA residence. In no other circumstances are separate apartment units considered a related site.

Skill training
This definition is incompatible with the "services and supports" terminology throughout the Rule; CILA services are intended to support people in their homes rather than continual pursuit of "optimal independent functioning". For example, does every person require a laundry, dish washing, room-cleaning, etc. goal? The term "skills building" was introduced previously in the definitions section. (See array of services.) A definition of this term would be helpful as it not the same as skills training, such as in ADL or IADL referenced in this section.

Support Services Team
We're unclear who this is and what they do.

Supported Relocation

The effort to address the circumstances as to how to intervene with a person who is a danger to themselves or others is appreciated but the definition needs further clarification. The procedures outlined should not be included in a written definition. It is recommended that the DD Division establish behavioral guidelines and that by whatever name these "guidelines" be referenced in the rule rather than the current procedures as presently included. It should also be recognized that a person to be relocated may be too upset or agitated to be confronted. It is not unusual to ask the other persons present to remove themselves from the area, rather than to risk physical harm. The 30-minute time-period should be expounded, e.g if a person is "relocated" to their bedroom, their selected quiet area, could they not remain in their bedroom more than 30 minutes? It is also not uncommon for a person to communicate their distress for more than 30 minutes and guidance should be included for these circumstances.

Time Out

Remove or define "period of time".

Volunteer

The definition must distinguish between those volunteers who have direct contact with the persons served from those who for example are doing yard work, painting the exterior of a house or building a deck. It is common within the CILA program for local businesses or companies to have employees who volunteer over a weekend to participate in the above examples—painting, raking, lawn mowing, shed building, etc. Sometimes the group is of large magnitude—8 or 10 persons. Such valuable contributions should not be lost to an agency because all of the volunteers did not have background checks run on them. It is our suggestion that volunteers not be involved in direct care activities, such as bathing, toileting or other areas where there is intimate contact.

Section 115.130 Rate Components

We advise removing this section from the Rule as it is informative but not regulatory in that it is not subject to review by BALC. Further, we expect significant changes to this section with the eventual enactment of Guidehouse recommendations.

**Subpart B Service Requirements**

**Section 115.200 Description**

a) We find the description to be aspirational vs. reflective of actual practice (e.g "choosing a home from among those living arrangements available to the general public…"). While we support the spirit and intent of such language it establishes a standard that is unenforceable.

b) Person-centered planning requirements are the purview of ISC agencies, not CILA agencies.

c)1d) Define "same degree of access" and how CILA providers will be measured to determine whether this is being met.

2) How will this be enforced is a person chooses a CILA home that does not provide the option for a private bedroom? What if a person agrees to a shared bedroom and later indicates they want a private bedroom?

5) How will this be measured? How will situations be addressed where housemates want to do different things but there is not adequate staff resources to support each person to do something?

6) What does this mean and how will it be measured? What if a person "chooses" not to attend CDS programming but there is not adequate staffing resources for them to stay home? What if a person "chooses" a person to provide services and supports that is not an option, such as staff assigned to a different home or supervisory personnel?

7A) How will a situation be handled where a person wants to remain living in Agency A's CILA home, but receive services from Agency B? What is expected from a CILA agency if 1 resident is abusing another resident? Per this section, the abuser cannot be forced to leave the CILA home despite another CILA resident being harmed by their presence in the home.

7B) How should CILA provider agency's perform bed checks if the bedrooms will be locked?

Bi) We have been informed that OSFM has contrary thinking on this item.

C/D) How are the rights of other residents of the CILA home balanced with these items, e.g an unwanted visitor (including real-life situations where the "visitor" is on the sexual offender

list)? Does this provision mean that people can choose not to attend CDS programming (or 37U) and the CILA rate will support sufficient direct staff personnel in the home? Can CILA provider agencies set time restrictions on visitors (e.g., not staying longer than 24 hours, no visits after midnight, etc.) What would prevent a "visitor" from taking up temporary residence in the home?

E) What is expected if a person acquires a physical disability, and the site cannot immediately be made accessible and/or if the $15,000 allocation for physical accessibility has already been spent or is insufficient to make the site accessible? The statement that an agency may decline services to an individual because they cannot accommodate a particular disability (type or level) has been removed. The rule should document the provider will determine if it can accommodate the needs of the individual.

F) The items outlined in this section are identified as components of the Personal Plan. As such, we expect that CILA providers are not accountable for documenting these steps and will not be subject to review of this section during surveys.

d) While we understand the intent of this statement, as a regulatory item, it demands definition (neither safety, well-being or involvement appear in the definitions) and caution that it is a highly subjective and difficult to measure statement. If a CILA residents' safety and well-being are compromised by a fellow resident's behavior toward him/her, what is the expectation for action on the part of the provider organization?

e) We strongly object to this item which reads that a CILA provider cannot decline services to a person they feel they are not qualified to support.

f) While not objecting to the sentiment of this section, we are unclear what regulatory intent is intended and how provider performance will be measured.

g) We advise adding "promote dignity of risk" to this section as the other values reflected necessarily impose some degree of risk to the person. For example, a person may "choose" to engage in a known risky activity with a likely unsafe outcome. As written, a CILA provider should/would not impede the person's decision based on this language.

i) It is unclear whether this provision applies exclusively to host home settings or all CILA sites. If the latter, it should be removed as aside from Rule 115 language, CILA providers must comply with DOL requirements and given the chronic DSP shortage, shifts in excess of 8+ hours is commonplace.

j) This section does not make sense and may be missing some content.

**Section 115.214 Additional Services and Support**

Add significant physical /sensory needs (blind/deaf requires hand over hand support) to the description. Add a single significant behavioral episode (e.g pushing a housemate down the steps resulting in death) that may justify additional supports. What is the role of the ISC, who is responsible for seeking appropriate services for the person? One of the primary recommendations there is a person served with enhanced medical or behavioral needs is to provide 1:1 support. This support would often be effective in managing the situation but due to the current staffing crisis we are almost never able to staff the position. This is a useless tool and recommendation if an agency is unable to provide it. Also, the real cost to the agency of providing that staff is never covered by the 1:1 funding because it only factors straight time and the shifts are always covered with overtime due to open positions. A premium rate should be given for 1:1 coverage with a faster roll in of a permanent enhanced rate. In this section, does "sudden intense behavioral episode" constitute a definition of imminent risk? What should occur if the behavioral episode does not subside?

A)2 It is recommended that the following language be inserted after 2 and before A: "Depending on the severity of the behavioral episode, (e.g. major physical harm to others, extreme property damage, etc), it may also be necessary and appropriate to consider discontinuation of services."

2B) CILA providers have no control over access to "needed medical services and supports" as evidenced by a statewide lack of adequate psychiatric services for people with I/DD. Providers should not be accountable for securing a resource over which they have no control.

C) Does the team decision have to be unanimous and what should be done if there is disagreement regarding the need for additional staff resources or supports?

E) What happens if the request for additional hours is not approved?

**Section 115.215 Criteria for Termination**

Our overwhelming reaction to this section is that it effectively outlines the current practices in place which do not work. The lack of an appeals process for CILA providers who feel they cannot safely support a person yet are denied the ability to discharge a person is untenable and forces CILA providers to invoke extreme caution in placement decisions. We advise 2 separate termination processes be developed via a focused committee of key provider representatives, DDD, BALC, BQM, ISC, OIG and E4E representatives. Further, the section needs to address the circumstance where 1 CILA resident is being physically or mentally abused by a fellow resident with specific consideration of the rights and wellbeing of the afflicted party being addressed.

It is strongly recommended that an appeal process be in place and included in Rule 115 that affords providers the opportunity to appeal a Department denial of termination of services. Such a request should be made by the provider directly to the Director within 15 days of the termination denial and be responded to in 15 days upon receipt. All denials of service termination should provide a full explanation for the denial. We recommend that in effort to minimize confusion and contradictions in practice that Rule 115 be compared to the Illinois ID/DD Community Care Act, with respect to matters of discharge from residential settings. Two distinct practices and approaches are not necessary today given the people served in these settings.

Once notice has been given to DHS and the ISA of a determination in the individual's health or behavioral issues and all of the steps have been met by the provider and the guardian has appealed and the department approves the guardian appeal, the provider should have the rights to appeal to an independent party such as a judge or mediator. This requires an unbiased person rather than the ISA and DHS representatives have often pushed the guardian to appeal even after the guardian agrees the situation is not favorable and that their loved one requires more than the agency can provide. By forcing the agency into this situation, it causes costly staffing issues, community and neighbor issues and gives CILA group homes negative public relations thereby causing resistance for people with DD being accepted by the community. This causes quality of live issues for the remaining residents in the home.

The current rule also includes "the individual no longer benefits from the services provided by the CILA agency." There are instances, in fact, when this is the case. Why was this provision deleted?

b A third consideration is recommended for termination: The individual and/or guardian refuses to follow significant medical/treatment recommendations that create legal liability for the Agency.

b2) If the provider is seeking to discharge because they cannot keep the person or others in the home safe, requiring them to do so as stated in this section is nonsensical. It is suggested that in sentence 1, the word "can" be replaced with the words "will seek to." An agency cannot know a priori that it "can" continue to serve…

c3) Clarify where lead responsibility for finding alternate placement lies. It is suggested that this paragraph be revised. A 30-day time period may be acceptable in routine circumstances with respect to discharging a person from a specific CILA. In other instances, however, such as the concern of preventing physical harm to others, a 30-day time frame is too lengthy. It is suggested that the end of the first sentence should read "…notifying the DDD in writing and will work to immediately secure an alternative placement."

c4) What timeframe is in place to resolve the situation? It is suggested that in this paragraph (4), the protocol referenced for "resolving issues or concerns" be included, not only for provider, guardian/individual knowledge, but also to ensure standardization of practice across the ISC Agencies.

c5) Division staff must be involved in this step. There have been instances when the Department has arranged a temporary placement for such a person in a State Operated Developmental Facility. Is that option being continued in the context of this rule?

g. How will this section be reconciled with the Guidehouse proposal to eliminate bedhold payment? Agencies should be able to terminate if medical needs warrant out of CILA placement beyond 60 as payment is no longer being rendered.

**Section 115.220 Services and Supports**

The language in this section implies that the CILA provider is responsible to assist people in finding CILA services; what role does the ISC play in this activity?

a) The language in this section doesn't reflect the definition and should be reconciled. Further we advise changing "develop" to "maintain" and change "service" to "support functions". Clarify the QIDP serves as Chair of this committee,

1. In the first sentence "service" should read "supports" to be consistent with the rule.
2. Change "know" to "known"; clarify to whom the needs are to be known. Are the assessed needs those that have been identified by the ISC Agency in the process of discovery?
3. What is the "array of community support services" the CILA agency is expected to assist the person to participate in? Continuously referencing the "guardian if applicable" seems to attenuate the rights of the person throughout the rule. An individual is allowed to make certain choices independent of a guardian.
4. What does access to SODC mean – temporary discharge?
5. "On a 24-hour basis" needs to be restated. The agency or provider has the 24-hour responsibility.
6. Advocate vs. advocating.
8. CILA payment does not include an "interdisciplinary process"; this is an ICFDD reference. If a site is individual-controlled, the provider is not responsible for assuring payment of rent or utilities, regardless of whether the person is present or absent
10. Eliminate employment references, this is a CDS/employment agency responsibility.
12. What is supportive counseling – MH term remove from DD regs.
15. This section needs clarification; what is expected of the CILA provider vis a vis SODC placement?
18. Resources must be provided to comply with this item, particularly for people who are non-verbal. Define healthy sexual practices.

c. QIDP vs. QDIP.

1) Change to 20 business days post receipt of the Personal Plan from ISC and remove date of provider signature page. "Develope" to "Develop"

5. We are unclear what is expected here; the Implementation Strategy address outcomes contained in the Personal Plan. Presumably the CILA provider has developed strategies to the best of their ability given available resources.
7. Does this mean monthly Q update?
9. We understand this to be CFCM functions.

**Section 115.225 Assessments**

"The agency…" – "Agency" is no longer a defined term. Please clarify if this is a CILA Provider Agency.

c)4 What is expected in the personal/family history?

5 We advise discontinuation of the SLOF as its' use and value is unclear. . If not discontinued, please clarify if providers are required to obtain a SLOF and an ICAP for people with MI.
Please confirm if the CILA Provider Agency or the ISC is responsible for completing the ICAP, as this is contradictory to the current Person-Centered Planning Process policy on the DHS website.

C6) If a person has I/DD but no MI, are providers able to pick and choose between a psychological and a psychiatric assessment?

7 These screens should be required only if MD says necessary.

d)4 Is this addressing the HRST and if yes, it should be identified as such.

5 Remove "as necessary" and replace with "as determined by the team".

Additionally, we find it unexpected that a risk assessment is not included in standard assessments and advise responsibility for completing this be addressed.

**Section 115.230 PCP**

a) Person centered planning is an ISC function, not CILA provider and as such should either be rewritten to reflect expectations for CILA providers once the person-centered planning process is completed or be removed. Term inconsistency with the definitions - "Agencies licensed to provide CILA services".

b)1 Restore the original 30-day timeframe and change to within 30 days of receipt of the Personal Plan. Add some language for development of a temporary Implementation Strategy if a current Personal Plan is not available to the CILA provider. Term confusion – "Agencies licensed to certify CILAs

and provide CILA services" – Does this mean CILA Provider Agencies? Is the person and their guardian required to participate in the implementation strategy?

b)2 The currently deleted language should be reconsidered; we think that this content is applicable to the functioning of the provider support team.

b)3 Same as above.

2A. Remove guardian from site selection.

3. Why would the person be given a copy of the Implementation Strategy and not the Personal Plan?

5D Define how long progress needs to be lacking before an update is warranted.

E. Further clarification of this language is needed for CILA providers to understand expectations.

6. Does the CILA Provider Agency need to notify the ISC if updates are made to the implementation strategy? The meaning of "function status" is not clear. Who has the responsibility for determining such changes?

7. Change "QDIP" to "QIDP"

9 Why is the statement in parentheses parenthesized? Replace agency with team.

**Section 115.240 Medical Services**

a. Community physicians do not assume responsibility for the program in which their patient lives as written here; this reference needs to be ne removed. Include Advanced Practice Nurse is list of licensed personnel.

d. Add APN designation. Change 6-month review to "annually or more frequently if directed by the prescribing professional".

e. Remove "competent" or list Advanced Practice Nurse and define.

h. This should be removed; the CILA agency does not control the prescribing physician and cannot be held accountable for this requirement.

Add language to permit CILA residents to be able to use technology in order to be independent in medication self-administration.

**Section 115.250 Rights and Confidentiality**

a. Please clarify – are CILA Provider Agencies expected to utilize the exact DHS Rights form, rather than providing the same information in a digestible format with plan language? Comment – would it not make sense for the ISC agency to provide a copy of the Rights form to the individual or guardian as applicable at the time they are meeting with them when completing the annual discovery process? This would seem to be more in line with conflict-free case management as presented in this document. "Enters the CILA and annually thereafter" needs a bit more definition—what does "enters" mean?

3)A To avoid any misunderstanding, it would be appropriate to add the clarification that a person who is a danger to themselves or others may in fact forfeit their right to live in a particular CILA, but not lose their right to participate in the CILA program.

3)C It would also be appropriate to add the following language after neglect: "and physical harm or mental injury from those individuals with whom they live." The rights of victims should be just as important as the rights of victimizers.

4. Remove reference to services plan. This item must include required communication with the CILA agency if other professionals are involved in service delivery. What accountability does the CILA agency have for implementing recommendations from unaffiliated professionals, particularly if they are contrary to the Personal Plan and/or Implementation Strategies?

b. Much of this section applies to ISC agencies that are responsible for the Personal Plan, not CILA agencies. This narrative needs to be clarified. Define "Employee advisement". The second sentence beginning with "For" is unclear, including an understanding of "additional".

d. The rule needs to clarify circumstances under which CILA staff may physically intervene with an individual to protect the person or others. Additionally, many CILA agencies use CPI or Safety First crisis intervention training and certification which does teach and employ some physical contact between staff and the CILA participant; clarification on the use of these certified techniques must be addressed.

## Subpart C General Agency Requirements

**Section 115.300 Environmental Management**

Gi-iv. We've commented previously on practical concerns with implementation of these requirements and how CILA providers will be held accountable.

Gii. OSFM lock/key requirements

A4) Are CILA Provider Agencies required to perform dills for intermittent CILA services and individually controlled sites? Must the drills be a drill or a training/meeting?

C6 d) iv) How will BALC surveyors measure sufficient light for reading?

7a. Clarify that all CILA sites do not need to be physically accessible.

H. We anticipate there will be disputes regarding the safety of expired food items and recommend a termination date be provided to assure compliance.

8E. Remove "volunteers" who should not be responsible for feeding people.

9f) Remove this item; if a site is individually controlled the provider should not be accountable for facilitating BALC visits.

**Section 115.310 Geographic Location**

a. This language is vague, subjective, and value-laden and should be removed. CILA homes should need to meet local zoning requirements only. Typically, CILA homes have been present in the community before becoming a CILA site therefore they are a part of the community and any distinctiveness has not previously "appreciably altered the characteristics of the neighborhood" and should not be subject to this standard once becoming a CILA home.

b. We advise removing this language as it is discriminatory and impedes the choice of people living in CILA settings. The HCBS Settings Rule addresses location of residential locations proximate to institutional settings only; people receiving CILA services should have the same choice as people not receiving CILA services to live near friends also receiving CILA services.

D1 Remove this provision as it is not a federal requirement; has a discriminatory impact by limiting choice and provides no consideration for existing homes to be grandfathered into compliance. Is this to literally mean that a person could not rent an apartment across the street from a community day program? Is the state of Illinois using these same guidelines for individuals with physical disabilities or the elderly who receive public funding?

3A-C Remove this language which goes well beyond the federal requirements and has a discriminatory impact on people receiving CILA services, some of whom may choose to live in rural settings that are not part of an immediate community.

e) Insert language to grandfather in existing apartment settings and to permit up to 8 CILA residents in smaller apartment buildings where the 25% maximum capacity will have a discriminatory impact on CILA residents, such as in low-income small developments where CILA participants would not be able to benefit from reduced rent due to the proposed 25% maximum capacity. It is our speculation that a "25% capacity of total units" may not be any more legally definable than the 800-foot requirement.

It is recommended that this narrative be rewritten. Note specifically lines 3 and 4. While it may be a "right" for a person to live "in the most integrated environment possible," it doesn't automatically follow that is their goal. It is recommended that the sentence beginning "Ways to accomplish this" be deleted. What should be emphasized is choice, self-determination, "the opportunity to participate in their community, interact with individuals who do not have disabilities, etc." Reference the following Department of Justice statement (Olmstead):

*"When enacting or applying zoning or land use laws, state and local governments may not act because of the fears, prejudices, stereotypes, or unsubstantiated assumptions that community members may have about current or prospective residents because of the residents' protected characteristics. Doing so violates the Act, even if the officials themselves do not personally share such bias. For example, a city may not deny zoning approval for a low-income housing development that meets all zoning and land use requirements because the development may house residents of a particular protected class or classes whose presence, the community fears, will increase crime and lower property values in the surrounding neighborhood. Similarly, a local government may*

*not block a group home or deny a requested reasonable accommodation in response to neighbors' stereotypical fears or prejudices about person with disabilities or a particular type of disability. Of course, a city council or zoning board is not bound by everything that is said by every person who speaks at a public hearing. It is the record as a whole that will be determinative."*

f)1 We repeat our comments above regarding the discriminatory impact of this newly proposed language.

**Section 115.320 Administrative Requirements**

b)2 Define "para-professionals". Volunteers do not (should not) provide direct service and such references should be removed throughout this section.

3 Remove this language and align with new law regarding use of criminal convictions in employment decisions.

c)1 Define the period of time that constitutes "cumulative case records".

c)2A) Remove the requirement that members not be shared among committees as there is no justification for this restriction and other credentials (BCBA) would benefit both committees.

c)2B)i Define frequency of required review by HRC.

iii) Remove this language; there is no need for the HRC to review positive intervention strategies and this would unduly burden the agency and HRC as positive strategies are used routinely throughout service delivery.

c)2C)i The requirement for a physician or pharmacist as a member of the HRC needs to be removed. There is no legal basis for this requirement and practically speaking, it presents an unattainable standard for CILA providers. If the language is retained, the state must make such professionals available to CILA providers through its' SODC network.

iv) This language does not make sense.

c)2Di Define the type of interventions that are subject to review by the BMC as routine service provision employs a variety of interventions including positive behavior strategies that presumably are not subject to review. "Behavior interventions" should be included in the definition section.

ii This same process should be included in the human rights committee Section C

iii We advise this language be removed from this section and inserted into the preceding description of HRC.

c)2Ei Remove reference to clinical psychologist as the CILA rate methodology does not pay for this service outside of direct client counseling and therefore, CILA providers do not have access to such expertise.

ii Remove this requirement per above comments regarding practicality of CILA providers retaining the services of a physician/pharmacist to serve on a committee. Further, medications are prescribed by a physician who treats the person and should be assumed as properly prescribed as in any patient/physician relationship. The Rule indicates the behavior management committee (and likely the HRC afterwards) would review interventions "when drugs to manage behavior are used." This has been historically interpreted by the department to mean ALL psychotropic medications are to be reviewed, for example, someone has a diagnosis of Depression and are prescribed an antidepressant and in psychotherapy, the HRC must review this. The department needs to specify what they determine "manage behavior" means as the most recent Human Rights Training Manual indicates the HRC must review all use of psychotropic medication. It is not made clear why use of psychotropic medication, prescribed by a psychiatrist for a mental illness, is a rights restriction or in need of human rights review. A suggestion is that the HRC or BMC are to review medications when, "It is not standard treatment or dosage for a client's diagnosed mental illness."

iv Same comment as above – the language as written does not make sense.

4A) Many CILA sites are gender-specific and therefore, do in fact limit admission based on gender; is this practice no longer permissible and how is this balanced against the preference of others in the home who prefer a gender-specific household. Additionally, this definition does not allow for compatibility among housemates to be considered in admission decisions.

- The numbering of this section is off in the Rule 115 draft – later lists section 4 as Admission to Programming but it is first listed as Abuse, Neglect, and Exploration.
- Please use "gender identity", not "gender"
- Please include ethnicity.
- Please include citizenship.

6 Include the names of authorized groups so CILA providers are able to comply

7 Further elaborate on the assessment process including nature of assessment, credentials for assessment, payment for assessment and who is responsible for assuring this is done. Clarify if the assessment process indicates the person would benefit from remote supports and payment cannot be secured to purchase/maintain such supports; what are the implications for the CILA provider in terms of complying with the Personal Plan?

d)1A Clarify the technique to be used.

B Most non-violent crisis intervention training includes physical contact/restraint techniques; clarify whether these techniques are permitted. It is also suggested that "non-violent crisis intervention" be expressed differently so as not to confuse the concept with a specific vendor. If the term "non-violent crisis intervention" is to be used, it should be included in the definition section.

F. It is suggested that this paragraph be re-written to reflect a greater regard for person-centered planning. What should be documented is the person's progress towards the outcomes they have selected/identified as reflected in the Implementation Strategy. The Implementation Strategy is not something that happens to people. The persons being supported should be active in making their plan happen.

G The state needs to develop training material in this area for CILA providers to use. The timeframe for reporting incidents is not listed here or in the definition of critical incident. Please provide the detail from the CIRAS handbook, including the incident categories, in the rules if providers are expected to adhere to them. See comments in the definition of critical incidents for clarification needed for specific incident categories.

K Change objectives to outcomes

I Change "Screening" to "Symptoms" as DSPs don't screen.

M Change direct care employees to DSPs to be consistent. This needs to occur throughout the rule.

e) Volunteers should not be providing direct care and therefore do not need training.

f) This requirement should be a deemed status consideration for CILA providers with accreditation.

H)3a Add "when available" following birth certificate.

H4f) Please clarify, do monthly QIDP notes need to include an indication of outcome progress, or only their involvement?

**Section 115.321 Employment Waiver (pg. 109)**

We refrained from commenting on this section as we expect it will be rewritten to comply with HB3653 which was signed into law.

**Section 115.326 Monitors and Receivership**

While we don't necessarily object to the intent of this section, we do question whether the state has the legal authority to direct operations of a private company. Recognizing the state's authority to rescind a CILA license and require a provider to cease operations, the imposition of a Monitor who directs the operations of a provider organization would need to be with the agreement of the organization. Should that not be provided we expect the state's option would be to remove CILA residents from provider-controlled settings, rather than assume control of those settings, which remain in the legal possession of the provider agency.

**Section 115.330 Accreditation**

As previously indicated, we recommend that accreditation of I/DD CILA providers be recognized by the state as there is not logical justification for discriminating against I/DD organizations when MH organizations benefit from accreditation status. This is not a definition of accreditation as written, only a reference to the Administrative Code. Many developmental disability providers are in fact accredited and this accomplishment should be recognized in the rule. Accreditation in this context is the formal recognition that an organization has attained and achieved a set of standards that improve the lives of the people supported that is beyond mere regulatory compliance.

## Subpart D Licensure Requirements

**Section 115.440 License Sanction and Revocation (pg. 133)**

- It is suggested that Rule 115 with respect to this section and the role of BALC consider alternative language with respect to the behavior being described in the rule. What is suggested is that, because BALC is conducting surveys and not investigations with respect to rule compliance, the most appropriate word to describe compliance, partial compliance or non-compliance is the word deficiencies. [See pg 2442, a) 3) "deficiencies."] A notice of "violation" seems inappropriate to a discussion of general and service requirements. This seems especially harsh when an organization is 85-92% in compliance.
- It is also recommended that DHS reconsider the current levels of compliance and the words used to describe them. Said another way, the words do not match the given percentages. The current approach does not represent a common taxonomy of standard accomplishment. It is suggested that a more appropriate and in-use "grading system" be utilized:

  Level 1: 90-100%
  Level 2: 80-89%
  Level 3: 70-79%
  Level 4: 60-69%
  Level 5: 60% or lower

  This approach would follow the typical academic grading system used in the United States, and one most Rule 115 users would be familiar with. Describing the percentages 85-92 as "partial" is not customary.

- Emanating from the above, it is suggested that a Level 1 of 90-100% would reflect "substantial" compliance with the CILA standards and no plan of improvement would be required from the Agency.
- A Level 2 of 80-89% would be "acceptable" compliance with the standards. The Agency would need to submit a plan of improvement within 10 days. A resurvey by the Department could occur within 90 days of the original survey, dependent upon the nature of the findings. It would be our view that even within the current approach, it is unnecessary to issue an administrative warning when an Agency scores in the 85-92% range. Does this policy follow the practice of other code departments?
- A Level 3 of 70-79% would be "borderline" compliance with CILA standards. The Agency would be required to submit a plan of correction within 10 days of receiving the BALC survey results. The BALC would issue a probationary license and prohibit new enrollments until the follow up survey occurs-within 60 days of the initial survey. We believe it is too harsh an action to suspend advance payments, especially at a time when providers are most vulnerable and unable to recruit sufficient members of staff.
- A Level 4 of 60-69% would be "unsatisfactory" compliance with CILA standards. The agency would submit a plan of correction within 10 days of receiving the BALC survey report. (Note a comment on the current Level 5 narrative with respect to the plan of correction. How will a provider know they have submitted an "acceptable written plan" before they submit it?
- Level 5 – see current Level 6 proposed.
- In summary, it is our thought that the use of the term "violation" is unnecessary and further terminations unnecessary during very difficult health & economic times. In the same fashion, terminating advance payments to a provider who is genuinely seeking to do their best seems more punitive than corrective.

## Subpart E Host Family Living Arrangement

Permit the option of host homes securing their own respite/relief staff with payment made by the agency as many host homes prefer to make these arrangements with people whom they know personally in the same way that HBS participants can secure their own PSW. Include the same training and background requirements for Host Home relief staff as is in place for HBS PSWs.