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Agency for Health Care Administration (AHCA)
Attention: HCBS Waivers
Mr. Nicholas Warner
2727 Mahan Driver, MS #20
Tallahassee, FL 32308

Email: FLMedicaidWaivers@ahca.myflorida.com

Re: Florida Statewide Transition Plan/ Developmental Disabilities Individual Budgeting Waiver (FL.0867)

Dear AHCA,

First, we would like to state that the whole premise of the Developmental Disabilities Individual Budgeting Waiver Transition Plan is dependent on Person Centered Planning (PCP) and that family participation is key. Without it the five objectives stated below are meaningless:

- Opportunities to seek employment
- Work in competitive settings
- Engage in community life
- Control personal resources and,
- Maintain the rights of privacy, dignity, respect and freedom

Unless residential providers encourage engaging with families -- exchanging information and sharing relevant documentation -- connection with HCBS is not possible. The voice of the family is particularly vital for those family members who have been adjudicated "incompetent." If family representatives meet resistance when attempting to schedule a meeting, are made to feel uncomfortable seeking information, and access to documentation is denied, we see practices more indicative of "institution" than HCBS.

It is clear that critical information can best be provided by family members through the PCP process. This is where legal representatives (parents, guardians, siblings, etc.) must speak to the specific individual's support needs, abilities, limitations, resources, and preferences for living, working and socializing. It must be clear what is important to that individual on a personal level, what meaningful inclusion is for this person, how this specific person experiences life and interacts with others and how and to what extent this individual engages in a positive way with the community.

(Cont'd.)

Providers should fully understand the role of legal representatives and family members in this process.

Both the Statewide Transition Plan and the DD iBudget Waiver Transition Plan must be strengthened to include mandatory comprehensive training to providers, consumers, families, and legal representatives in the specifics and the requirements of the Person Centered Planning Process.

The primary Federal authority for participation in the PCP vests in the actual 2249F regulation as recorded in the Federal Register, Vol. 79 Issue 11 (1/16/2014)
<http://www.gpo.gov/fdsys/pkg/FR-2014-01-16/html/2014-00487.htm> at page 3029, Sec 441.301:

Among the waiver regulations under this subpart, it specifically states:

(c) (vi) Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan, except when the State demonstrates that the only willing and qualified entity to provide case management and or develop person-centered services plans in a geographic area also provides HCBS.

To address these critical concerns, it is imperative that clients' legal representatives be aware of their options, e.g.:

1. From Assisted Living Facility & Adult Family Care Home Residents' Rights – Residents' Bill of Rights Florida Statutes 429.48

Every resident shall have the right to present grievances and recommend changes in policies, procedures, and services to the staff of the facility without restraint, interference, coercion, discrimination or reprisal. This right includes access to ombudsmen volunteers and advocates and the right to be a member of, to be active in and to associate with advocacy or special interest groups.

2. From APD: the Bill of Rights of Persons with Developmental Disabilities. Florida Statute 393.13:

The client, if competent, or the client's parent or legal guardian if the client is incompetent, shall be supplied with a copy of the client's central record upon request.

3. From AHCA, June 19, 2014:

. . . the Centers for Medicare and Medicaid Services (CMS) passed a rule about how states offer Home and Community-Based Services The new rule means you get your services from providers who

- *Work with you to make your plan of care; Make you feel at home if you live in a group home, assisted living facility, or adult family care home;* (Cont'd.)

- *Help you be part of your community; and*
- *Help you choose how you live and what you do.*

4. From Fact Sheets: Home and Community Based Services:

<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/final-rule-fact-sheet.pdf>

Person Centered Planning

In this final rule, CMS specifies that service planning for participants in Medicaid HCBS programs under section 1915(c) and 1915(i) of the act must be developed through a person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals. The rules require that the person-centered planning process is directed by the individual with long-term support needs, and may include a representative whom the individual has freely chosen and others chosen by the individual to contribute to the process. . . .

The Second Major Point of this commentary relates to documentation as part of a central file.

Residential Habilitation (Habilitation Plan) Form ID: HABP-BGVFL-C8C4RZCZS7677 details documentation procedures that are to be used. For example, in Section 2: Skill Acquisition/Retention:

If resident declines the step and declines for staff to assist him, staff will score the task as ‘Declined.’ Staff will then write in the comments section how they attempted to assist the resident. What they said and did. What resident’s response was, and how he declined (verbal gesture, ignored, etc.).

Specifically, the Federal requirements (AHCA) regarding HCB services Home and Community-Based Settings Rule Quick Reference state:

Any modification [to] setting requirements must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

- *Identify a specific and individualized assessed need.*
- *Document the positive intervention and supports used prior to any modifications to the person-centered service plan.*
- *Document less intrusive methods of meeting the need that have been tried but did not work.*
- *Include a clear description of the condition that is directly proportionate to the specific assessed need.*
- *Include regular collection and review of data to measure the ongoing effectiveness of the modification.*
- *Include established time limit for periodic reviews to determine if the modification is still necessary or can be terminated.*
- *Include the informed consent of the individual.*
- *Include an assurance that interventions and support will cause no harm to the individual.*

(Cont’d.)

Again, both the Statewide Transition Plan and the DD iBudget Waiver Transition Plan must be strengthened to require consultation with family &/or legal representatives regarding any assessment process which may lead to modifications of the person-centered service plan. Meaningful consultation requires access to all documents in the individual consumer's central file and a free exchange of information between the parties.

The **Third and Final Commentary** is specific to the Florida Statewide Transition Plan (Home and Community Based Settings Rule CMS 2249-F and CMS 2296-F) (Draft February 12, 2015) http://ahca.myflorida.com/medicaid/hcbs_waivers/docs/transition/Draft_Statewide_Transition_Plan_02-12-2015.pdf

Our comments relate particularly to the individuals in a residential HCBS whose language and communication / intellectual skills render them incapable of benefitting from the standard expectations of the questions:

Attachment III

1.1 Is the setting on a gross lot area exceeding 8 acres?

Comment: Size of the setting may enrich or limit activity and enjoyment of a property and in no way implies a restriction to community integration. On the other hand, there are no requirements for a group home to have at least a back yard. Why is choice denied to residents with disabilities when there are no restrictions other than local real estate laws for the general population who choose planned residential communities?

1.1 Is there an ADT program, or a licensed residential facility on the same or adjacent parcels of land?

Comment: Limited intellectual capacity renders some residents at serious risk if expected to benefit from a resource that requires travel in order to “integrate” them with the community at large. Additionally, transportation costs and programming requirements add to the difficulty of accessing a “community” ADT, and achieve no significant integration as a result of shuttling them back and forth.

4.2 Are individuals made aware of community activities via a community board, flyers, etc.?
Expectations are that individuals are consulted in selecting, planning and scheduling organized activities.

How does the facility facilitate individual access to community activities?

Where is the activity calendar posted; how often is it updated?

Does the facility organize activities, or facilitate access to activities of individuals' choosing?

Comment: Not only should community activities be posted and distributed by flyers, etc., but require provider's signature that the resident who is unable to read was told of each activity and resident's name was added to sign-up sheet if willing, e.g. walks to gym, shopping, etc., travel to community events.

4.5 How does the facility organize appropriate transportation to community activities?

Is transportation provided or arranged by the facility to community activities?

(Cont'd.)

Does the facility have a sign-up sheet and information about provided transportation accessible to individuals?

Comment: Transportation should accommodate the number of persons on the sign-up sheet. Transportation vehicles should be available by the provider or provided if a larger number is signed up. Documentation should state that the resident was informed of an event and included in the activity.

5.3 Is information about filing complaints posted in obvious and accessible areas?
Are individuals comfortable with discussing concerns?

Comment: Information should be posted. It should also be issued to authorized representatives who may speak for individuals. Individuals and their representatives should feel comfortable with discussing concerns and should not be questioned or grilled before a meeting is arranged.

5.5 Does staff ask the individual about their needs/preferences?
Are individuals aware of how to make service requests?
Are individuals satisfied with the services/support received and those who deliver them?
Are individual requests accommodated?

Is individual choice facilitated such that the individual feels empowered to make decisions?
Can the individual choose from whom they receive services and supports?

Comment: Individuals and their representatives should feel free to approach providers to discuss service requests or to submit them in writing. Providers should welcome opportunities to expand and tailor services and to discuss opportunities with individuals.

5.6 Are individuals, or their delegate, an active participant in the development of and updates to, the person-centered plan?

Is/are the individual/chosen representative(s) aware of how to schedule a person-centered planning meeting?

Can individuals explain how they would initiate a person-centered plan meeting/update?

Was the individual/representative(s) present during the last person-centered plan meeting?

Do planning meetings occur at times convenient to the individual/representative(s)?

Comment: Authorized and/or legal representatives may speak for resident who is incapable of verbally communicating. Requests for meetings with providers to discuss any issues of immediate concern should be provided as part of an ongoing person-centered planning process.

6.2 How are modifications to the HCB Characteristics addressed and documented?

Comment: An amendment to Chapter 419 FS allows the establishment of planned residential communities for persons with developmental disabilities and exemption from the thousand foot rule, requiring that community residential homes be separated from each other by 1,000 feet. Data to support such a residential community are evidenced by the wide support of the Florida legislature to grant freedom to choose the same living conditions as those in the general community – move on the grounds freely, ride bicycles, play softball, have a learning center, etc.

Attachment IV

2.2 Settings options are identified and documented in the person-centered plan and are based on the individual's needs and preferences. (Cont'd.)

Does the service setting and service provision afford individuals the opportunity for individual schedules that focus on their needs, desires and self-growth?

Comment: Opportunities for scheduling of activities should be available. Opportunity for Life Skills Development is necessary and will provide the resident with the availability and support of a Companion who accompanies the resident to places and events in the community and which provide meaningful inclusion. This should be available with authorization from the individual's Med Waiver.

3.2 The setting optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices including but not limited to daily activities, physical environment, and with whom to interact.

Comment: We recognize the need for settings that provide safety, fellowship, freedom, independence and choice of activities for self-growth. Individuals with special needs have the right to the same choice of life style available to all citizens.

3.3 Choice of service providers and settings are offered at the beginning of each authorization period.

Comment: Individuals should have opportunities to express their satisfaction or dissatisfaction with their service provider and exercise their right of choice to alternatives.

In Summary, with respect to the HCB Characteristics Review Tools (Attachments III and IV), we recommend the following :

- Delete all references to arbitrary, non-relevant criteria (e.g. gross lot size, physical "location" of an ADT).
- Expand expectations to reflect the needs of individuals with severe communication difficulties and support needs (e.g. telling them about activities, signing them up when they choose to participate and then arranging for them to be safely transported and properly supported by appropriate staff).
- Be clear and specific throughout that consumers have a fundamental right to be free from coercion and intimidation, to express concerns, dissatisfaction, file complaints, and initiate and participate in meetings.
- Affirm that these rights extend to their legal representatives and family members who speak for them, advocate for them.
- Clarify and specify throughout that individuals with waiver funded supports have the same rights of choice as people without disabilities. Settings and services chosen must reflect their personal experiences, goals, and interests.
- Clearly establish that "Person-Centered" is the key. Respect that. Reflect that in all standards and expectations.

Thank you for your consideration of these comments and recommendations. Please address them in the revisions to the draft transition plans.

Lila Klausman, Pres.

Parents Planning Programs for the Developmentally Disabled of Florida, Inc.