FLORIDA HEALTH JUSTICE PROJECT, INC.

March 26, 2020

Comment regarding Proposed Rule 59G-4.193, F.A.C. published March 4, 2021

Submitted electronically to Medicaid Rule Comments@ahca.myflorida.com

Dear Friends,

The Florida Health Justice Project (FHJP) is a Florida based 501c(3). Our mission is to help ensure increased access to health care and improve health equity for Florida's most vulnerable populations, including seniors and persons with disabilities who are in need of home and community based services (HCBS). We very much appreciate the opportunity to submit comments regarding the proposed rule. We also appreciate the opportunity to participate in the March 25, 2021 Public Hearing. However, we also want to express our concern about the recently concluded Public Hearing. Specifically, while FHJP had several unanswered questions in the question box, the moderator for the hearing incorrectly stated that there were no more pending questions. Indeed, I was hurriedly typing into the question box protestation that my question(s) had not been answered. Please let us know if this failure was due to technical difficulties. If not, we would very much appreciate an opportunity to discuss our questions.

Rule Comment:

As an initial matter, we note our full agreement with the attached comprehensive comment letter submitted by Elder Law Section of the Florida Bar. Katy DeBriere, undersigned Legal Director, worked on these comments. We also note our appreciation of the Agency's response in the March 25 hearing stating that the rule drafters would address the issue flagged in the Elder Law Section's comment regarding the definition of an "APS High Risk Referral" as someone age 60. As the comment letter set forth, there is no authority for that age distinction in the statute.

We understand that the new rule is being promulgated pursuant to the 2020 amendment to Fla. Stat. §409.979 regarding notification of waitlist placement. Presumably, the legislation's intent was to avoid placing individuals with a "low priority score" on the waitlist. This was understandable given that individuals with low scores are not released from the waitlist.

However, the proposed draft rule fails to ensure that the notice described in section (3)(d) will be provided to all applicants, including those with a low score. This violates requirements in federal Medicaid law. *See, e.g.* 42 U.S.C. § 1396a(a)(3). All of the information specified in the draft at section (3)(d)1-6 must be contained in the notice and must be provided to everyone. As FHJP stated in our September 18, 2020 comments, due process requires that all post-screening notices, including those provided to persons with a "low priority score," be provided with the requisite information.

We have included suggested changes[i] to the proposed amendment that would address this specific concern. Section (3)(d) from the proposed rule is excerpted below. In order to differentiate FHJP's

comments from those in the proposed rule, additional language is highlighted in yellow and deletions are highlighted in red.

(d) When the screening process is complete, DOEA will provide the all individuals, including those with a low score, or their authorized representative, written notification of ~~wait list placement including~~ all of the following:

1. For individuals with a high priority rank, notification of wait list placement.

2.~~1.~~ The individual's priority rank.

3.~~2~~. Contact information for the ADRCs.

4.~~3.~~ Instructions for requesting an administrative fair hearing in accordance with Title 42, Code of Federal Regulations (CFR), Section 431, Subpart E.

5.~~4.~~ Instructions for requesting a copy of the completed screening tool, which includes the priority score.

6.~~5.~~ Instructions for requesting a rescreening. The individual, or their authorized representative, may request a rescreening due to a significant change.

7. For individuals with a low priority rank, written notice will include all of the information specified in (d)1-6, as well as notice of notification of ineligibility for wait list placement and information on how to find community resources available to assist them.

We also recommend that the DOEA notice contain a statement that an individual has the right to seek the assistance of an attorney with a link to Florida's legal aid directory.

Thank you so much for your consideration of these comments, along with those submitted by the Elder Law Section of the Florida Bar.

Sincerely,

Miriam Harmatz

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Katy DeBriere
Legal Director

[i] Again, we note our agreement with the Elder Law Section's comments, which provided a complete rewrite of section (3)(d). We offer these more "surgical" comments as another suggested approach for addressing our concern that the current draft fails to clarify that those applicants with a low score are entitled to the same notice information as those with a high score.

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THE FLORIDA BAR
ELDER LAW SECTION

The Elder Law Section cultivates and promotes expertise and professionalism in the practice of law affecting people as they age and individuals with special needs.

March 22, 2021

To: Agency for HealthCare Administration

RE: Comments on Proposed Rule 59G-4.193, F.A.C. published March 4, 2021

Dear Agency;

I write to you as the Chair of the Florida Bar Elder Law Section, The Elder Law bar serves its clients by providing legal services for the Elder and disabled population in the State of Florida.

The following comments are provided on behalf of the Elder Law Section of the Florida Bar regarding the proposed changes to Rule 59G-4.193, F.A.C. published by the Agency for Health Care Administration (AHCA) on March 4, 2021.

We understand that the impetus for this proposed rule is the statutory change made to Fla. Stat. §409.979, concerning administration of the wait list for individuals seeking enrollment under the Medicaid Long-Term Care Waiver ("LTC Waiver"). Some of AHCA's proposed changes, however, are inconsistent with the legislative mandate and others either need clarification or may risk running afoul of other state or federal authority.

Below we review the Proposed Rule, addressing both the suggested amendments and related issues needed to clarify or correct long-term problems.

Subsection (2): Definitions

(a) APS High Risk Referral has been defined as "Individuals age 60 or older who are determined by Department of Children and Families Adult Protective Services to be victims of abuse, neglect, or exploitation, who need immediate services to prevent further harm."

Limiting the age for "High Risk" referrals is nowhere suggested in Fla. Stat. §409.979. APS has authority over all adults, including younger vulnerable or disabled adults. *See e.g.*, Fla. Stat. §415.102(28). The LTC Waiver's enrollee population includes age 18 and over. There is no

statutory support or other justification for limiting this category to a particular age group.

(e) Since a distinction must now be made between "high" and "low" priority as now required pursuant to Fla. Stat.§409.979(3)(a)(4)(b), we do not object to defining 3 and up as "high priority" with appropriate safeguards in place for "low" priority and with steps taken to correct the current deficiencies in the screening process set out below. Without changes to the screening tool, the scoring of "high" and "low" will be arbitrary, at best, and inaccurate, at worst.

High priority rank is defined as "automatically generated." However, Ranks 6, 7 & 8 are not automatically generated but based on agency referrals (Ranks 6 & 8) or specific criteria beyond the priority scoring algorithm (Rank 7, Imminent Risk). Rank 7 is determined subjectively and often requires supervisory approval. In addition, we are aware that the screener does not even ask some of the criteria for Imminent Risk (such as financial strain or pending eviction from a nursing home); to qualify an individual would need to volunteer information. For Rank 7 to be "automatically generated," the 701S Screening Form would need to be redesigned to cover Imminent Risk criteria and should be validated for consistency of results.

Rank 7 is only rarely used. In September of 2020, only 8 individuals were ranked as 7 for the LTC Waiver. We would like to see AHCA evaluate Imminent Risk of placement in a nursing facility in a less arbitrary fashion, including giving the individual being screened appropriate questions to assess that risk and a validated tool to make that assessment. The current Imminent Risk criteria is too limiting, particularly its arbitrary requirement that an individual's condition must be "worse" and its tie-in to the requirement that a primary caregiver be "in crisis." (See discussion below in Problems with Screening Process section.)

(g) Low priority rank definition: no objection given the same caveats stated with regard to paragraph (e) above.

Subsection (3): Process

(a) As we currently understand the process, an individual seeking to be screened for the LTC Waiver must call the ADRC and specifically request that they be screened for this program. This is problematic for many reasons, including the fact that the "Waiver" or HCBS portion of the LTC Program has no official title. Because individuals may not know the name of the program or otherwise understand how to request assistance, we ask that AHCA draft a short explanation to guide the ADRC about when they should screen for the LTC Waiver waitlist even if not explicitly or directly requested.

(d) Thank you for clarifying that the notice for persons screened must be in writing. Since both high and low priority information is listed in this subsection, it is assumed that the individuals with a low priority rank will also be notified in writing. Please clarify if this is incorrect.

(d)(4) In addition to the citation to Title 42, Code of Federal Regulations (CFR), Section 431, Subpart E – please cite to the Florida statutory and administrative rules which establish that requests for administrative fair hearings shall be submitted and heard by the DCF Office of Appeal Hearings.

(d)(7) This amendment states that individuals with low priority rank will only receive notification of ineligibility for the wait list and information on how to find resources available to assist them. This leaves out a statutory requirement that persons with low priority scores be informed "that they may contact the aging resource center for a new assessment at any time if

they experience a change in circumstances." Fla. Stat. §409.979(3)(b).

While notice of an individual's rank and scoring is now currently required (and has been since this Rule was effective in December of 2016), this is not happening. We are aware that DOEA has developed a new notice template that would include this information when an applicant is screened. Copies of these new DOEA notices are attached. However, the new template still does not provide information on fair hearing requests, except to refer individuals to a website. This is not sufficient given that the population being served is low income, disabled and elderly. Many of these individuals do not have ready access to the internet.

We also recommend that the DOEA notices contain a statement that an individual has the right to seek the assistance of an attorney with a link to Florida's legal aid directory.

Even if priority rank and score are provided, this information is not adequate to allow individuals to understand if the score or the recorded response is accurate. The only way that could be determined is to send a copy of the screening tool itself.

This is how we recommend the rule be redrafted:

59G-4.193(3)(d)(7): When the screening process is complete, DOEA will provide the individual, or their authorized representative, written notice as described below. Forms for these notices are incorporated herein by reference.

1. For all individuals, DOEA's written notification will contain:
(i) The individual's priority rank.
(ii) Contact information for the ADRCs.
(iii) Instructions for request a rescreening. The individual, or their authorization representative, may request a rescreening due to a significant change. [note that this will include individuals that score as low priority which is required per Fla. Stat. 409.979(3)(b)].
(iv) Instructions for requesting an administrative fair hearing in accordance with [FL statutory & administrative rule] and Title 42, Code of Federal Regulations (CFR), Section 431, Subpart E.
(v) A copy of the completed screening tool, which includes the priority score.

2. For individuals with a high priority rank, in addition to the information in Fla. Admin. Code. R. 59G-4.193(d)(7)(1), DOEA will also include notification that they have been placed on the LTC Waiver wait list and will be contacted annually to be rescreened.

3. For individuals with a low priority rank, in addition to the information listed in Fla. Admin. Code. R. 59G-4.913(d)(7)(1), DOEA will also include notification of ineligibility for wait list placement and information on how to find community resources available to assist them.

Subsection (4): Bypass of screening

There is no mention of "a nursing facility resident who requests to transition into the community and who has resided in a Florida-licensed skilled nursing facility for at least 60 consecutive days." While the Rule does state that it does not apply to ICP recipients, it is not clear how this exclusion relates to the criteria for bypassing screening, and the process for assuring that this occurs has not be formalized. Adding the statutory exemption will do no harm and will provide

valuable information to agency personnel, providers, advocates and applicants. Please take this opportunity to include this important provision in the Rule.

We also request that the Rule include a formalized process for application to the LTC Waiver when screening is bypassed. Currently, there is little consensus on how this process should work and individuals seeking to directly apply for the LTC Waiver are often given conflicting advice on how to proceed. We believe that individuals in a nursing facility should work through their LTC Program managed care plan case manager, and that children with complex medical needs would similarly seek the assistance of their MMA case manager. However, these avenues often break down. Please explicitly set out the process for direct application for each bypass group.

We have also reviewed AHCA's new website that is meant to educate individuals about the waiver application process. This website can be found at: https://ahca.myflorida.com/medicaid/statewide_mc/smmc_ltc.shtml.

In comparing the language of the website to the proposed rule, we want to raise a couple additional concerns:

First, the website states that an administrative hearing is available only to challenge whether screening answers were recorded correctly. However, an administrative hearing would be required to challenge any erroneous agency action. AHCA should clarify both in rule and on the website.

Second, the website states that only individuals age 18, 19, and 20 who are receiving private duty nursing will be considered eligible to bypass the screening and waitlist process to enroll in the LTC Waiver. This is an overly restrictive interpretation of the statutory language at Fla. Stat. §409.979(f)(1) which is correctly incorporated into the proposed rule. Please make sure you correct the language on AHCA's website.

Problems with Screening Process

The current adopted form (701S) and priority scoring for screening are over 20 years old and are in need of revision.

The current scoring system places a very high emphasis on the confidence of a caregiver to continue to provide care. This question, in itself, is responsible for arbitrary ranking results that have no relationship to an individual's actual need for services. As Elder Law attorneys, we have all encountered caregivers who will flatly refuse to say, under any circumstances, that they are "not very confident" of continuing to provide care, even when the care they are providing is physically harming both themselves and their loved one. As an example, the elderly wife of a man who was bedbound believed that her marriage vow prohibited her from ever saying that she would not care for her husband. Nonetheless, she was unable to turn her husband resulting in his repeated hospitalizations for life-threatening bedsores. Other caregivers are unwilling to admit to being overwhelmed when asked the question in front of the person they are caring for (which is frequently done in screening). Still others are terrified that an admission that they are not very likely to continue to provide care will result in being reported to Adult Protective Services.

This heavy reliance on caregiver confidence is not supported by any assessment of the quality of care, the real-life burden on the caregiver, or the safety of the caregiver or the applicant. There are no questions about hospital admissions or trips to the emergency room. There are no questions about calls to paramedics (frequently a sign that the applicant is a fall risk and that the

caregiver is unable to manage that risk). There are no questions about the frequency of care during the night that results in caregivers being chronically sleep-deprived.

Under current scoring, many of the ranking questions revolve around a "primary caregiver." Despite its weight in scoring, the term "primary caregiver" is not defined unless an applicant thinks that they have one. We believe that, in addition to defining "primary caregiver," the screening tool should include a question about the identity of the primary caregiver and the caregiver's relationship to the applicant.

There are no direct questions about financial stress, which must be volunteered, and even then, only if the caregiver states they are not very likely to continue providing care.

The scoring also artificially lowers the scoring for applicants with even severe dementia, who still might be physically robust but often require a high level of care and supervision, sometimes throughout the day and night. For example, having hallucinations at night, chronic insomnia or night terrors, or consistently getting lost or wandering away all demonstrate the severity of cognitive disabilities that require HCBS intervention even when other physical disabilities are not present.

While it may be appropriate to inquire into income and assets to gauge whether a caregiver is under financial duress, the ADRC should never screen the individual for potential financial eligibility for the Medicaid program or inform the individual that they do not meet the income or asset criteria for the Medicaid program. That information should be processed and collected at the time the individual files an application for Medicaid with DCF ACCESS. Questions about income and assets can have the effect of discouraging people from applying for the LTC Waiver.

We also are concerned about ensuring an individual has the proper assistance and representation with a screening. With the consent of the client or the client's legal representative, there must be leeway to allow participation by caregivers, family members, providers, elder law and legal aid attorneys, and others who are knowledgeable about the individual's care needs. In terms of continuing contact with the ADRC, the rule should incorporate a reference to 42 CFR §435.923 which sets forth how authorized representatives are appointed for purposes of a Medicaid application. Once an individual has notified the ADRC of the appointment of an authorized representative, the ADRC shall communicate with that individual as well as the client. It may be useful for the ADRC to develop a form to be maintained in the file notifying them of who to contact in regards to waitlist screening and enrollment.

In regards to rescreening, a change of circumstances should include a change in financial circumstances. Some individuals do not understand that, as their finances change due to paying privately for care, this is an acceptable reason to request a rescreen and have their priority scoring re-assessed.

We thank you for your consideration of these comments. If you have questions or need further information, please contact Heidi M. Brown, Esq, Chair of the Elder Law Section Medicaid Committee at HeidiB@omplaw.com.

Sincerely,

Steven E. Hitchcock, Esq. LL.M.(Elder Law) BCS (Elder Law)
Chair for the Elder Law Section of the Florida Bar (2020-2021)