Disability Rights
ARKANSAS

Tom Masseau, **Executive Director**

July 25, 2018

Division of Medical Services
Office of Policy Coordination and Promulgation
P.O. Box 1437, Slot S295
Little Rock, Arkansas

Re: ARChoices 1-18

Dear Sir or Madam:

Disability Rights Arkansas, Inc. (DRA) is the federally authorized and funded nonprofit organization serving as the Protection and Advocacy System (P&A) for individuals with disabilities in Arkansas. DRA is authorized to advocate for and protect human, civil, and legal rights of all Arkansans with disabilities consistent with federal and state law.

DRA thanks you for the opportunity to comment on the proposed rulemaking regarding the ARChoices in Homecare and Home and Community-Based 2176 Waiver, Rule 212.100. That said, DRA questions whether this is a genuine opportunity for public comment, as DHS has been using this methodology for allocating attendant care hours since 2016, and has expressed no intention of changing any part of the rule based on comments received. In addition, this is an issue that our agency and others brought to DHS's attention more than one year ago; consequently, this is a problem created by DHS's unwillingness to apprise the public of its rules that govern changes to these life-saving services in a way that is not only transparent, but also legal.

RUG Overview

The first section of the proposed rule provides an overview of the RUGs system, the purpose behind it and the purported effect it will have on the delivery of attendant care for individuals receiving ARChoices Waiver services. DHS briefly described the methodology used to establish the number of hours supplied to each RUG as data-based. DHS relied on "DAAS recorded beneficiary RUG placement and the number of

paid attendant care hours utilized by beneficiaries each month" between 2013 and January 1, 2016, to create an average that was then assigned to each RUG. DHS has represented to us that the data no longer exists; accordingly, it is not verifiable. We have no way of knowing whether those persons who received fewer hours than their peers suffered adverse health outcomes between 2013 and January 1, 2016, because of the disparity in care. We have no idea whether those persons who were receiving fewer hours ultimately required institutionalization or were satisfied with the number of hours they received. Further, the problem of absent paid claims data is compounded because there are a number of reasons a claim might not have been paid. If a caregiver calls in sick for one day, it could result in the reduction of eight hours of care to an individual that affects the average. Consequently, the lack of data regarding the process used up to the date ARChoices was initiated not only evidences a problem in the validity of the data in how it is being used to formulate the hours assigned to each RUG, but it also represents a lack of evidence that the rule is intended to solve any problem that actually existed, as opposed to merely one that DHS perceived.

DHS states that "the reality of living with a disease or condition can vary greatly even among individuals with the same diagnosis." This statement represents how important the collection and maintenance of data would be, as opposed to the memory of data that once existed. Despite their understanding of the variance of needs among individuals, with this rule DHS intends to lump more than eight thousand individuals into only twenty-three categories. This proposed system yields confounding results, which will be discussed below, contrary to DHS's stated purpose for the rule.

One of the founders of the system, Brant Fries, described DHS's swift move from one of nurse discretion to the proposed rigid, automated operation of an algorithm as "stupid," and advised against it.[1] DRA has handled several appeals for individuals who DHS nurses previously evaluated as requiring the maximum number of hours available through ARChoices for 2015-2016, but, by operation of the algorithm and assignment to a RUG, the individuals' hours were typically reduced by nearly half. While DHS indicated that this reflects the problem of using nurse discretion, they maintained no data to support this position. Instead, they request that the public simply accept their conclusion as true.

---

[1] Lecher, Colin, *What Happens When an Algorithm Cuts Your Health Care*, March 21, 2018, https://www.theverge.com/2018/3/21/17144260/healthcare-medicaid-algorithm-arkansas-cerebral-palsy, last accessed, July 24, 2018.

In addition, the RUGs system, as DHS is proposing, does not permit any evidence from a medical care provider to challenge the medical necessity of attendant care hours in a greater number than those that are assigned to a RUG. The inflexibility of the system is also contrary to Brant Fries's user's manual for administering the assessment. The manual states, "[the assessment does not] include all of the information that might be necessary to construct a comprehensive plan of care."[2] Further, the manual indicates that it is necessary to supplement what is learned through the assessment with information relevant to the individual.[3] To transition from a program that was based entirely on the training, education, and experience of a medical professional who personally evaluated and made an individualized assessment of a person's needs, to a program that allows for no exception, variance, or discretion based on special circumstances is both dangerous and irresponsible.

<u>RUG Requirements</u>

The "rule book" provided by DHS is also problematic. At the outset, it is almost as difficult to read and understand as the algorithm itself. In addition, many of the areas of questioning only capture treatments or conditions that existed three days to a week preceding the assessment.[4] An individual's year-long care plan is then developed based on data that might only capture a few days' worth of relevant information about that individual, instead of utilizing nurse discretion, which could evaluate the entire individualized picture of a person's needs. Further, it yields sometimes illogical results that do not adequately address an individual's needs.

One specific problem that is apparent from review of the proposed rule is the order in which individuals are removed from the algorithm. The rulebook states that an individual is placed in the first RUG for which they are eligible according to the listed chart. Following that instruction as stated, if an individual receives at least 120 minutes of Speech, Occupational, or Physical therapy in the week preceding the assessment, they must fall into one of three "Special Rehab" RUGs regardless of any other conditions they might have. Those hours are fixed at 157 hours, 97 hours, or 55 hours, depending on one's ability to perform activities of daily living.

---

[2] Morris JN, Fries BE, et al. *interRAI Home Care (HC) Assessment Form and User's Manual*, Version 9.1. Washington, DC: interRAI, 2009, p. 2.

[3] *Id.*

[4] I.e., an individual who had a fever in the preceding three days and reports weight loss of 5% will receive a score of 1 in special care. This mere presence of a fever within three days of one's assessment could be the difference between 161 hours per month and 137 hours per month. If a person then develops a fever, the recourse is to request a reassessment, which may or may not occur before the fever subsides.

The restriction on when therapy services were used, in this case "in the week preceding the assessment," will affect the individual's attendant care hours for the entire subsequent year of the person-centered service plan. This can result in fewer hours for an individual who might otherwise qualify for a different RUG if not receiving therapy. If an individual has quadriplegia, utilizes parenteral feeding,[5] and has used any one of the "extensive care" treatments[6] within the three days preceding the assessment, they would otherwise qualify for up to 352 hours per month under extensive care if they were not trying to improve their communication with speech therapy. If that same individual received 120 minutes of speech therapy, those 352 hours would be reduced to 157.

Another problem is the weight applied to parenteral feeding. Some individuals who DRA represented qualified for parenteral feeding, but due to the risk of infection and the desire to continue tasting their food as long as they were able, chose to continue receiving assistance with eating. While parenteral feeding is almost necessary to receive the maximum number of hours of attendant care, it does not take as long to finish a meal. The RUGs system, in essence, punishes clients for taking a less risky and less restrictive alternative that typically will result in a better quality of life, at a sacrifice of fewer hours of attendant care.

Individual Impact

DHS's use of the Resource Utilization Groups (RUGs) system has already had a tremendously detrimental impact on the individuals with disabilities that DRA serves and does not better reflect a beneficiary's needs as DHS asserts in these rulemaking documents. In fact, the use of the RUGs system, as currently proposed and as illegally implemented prior to this rulemaking process, has resulted in drastic cuts to DRA's clients' hours. These clients have been receiving ARChoices Waiver services for many years, each being assessed by a DHS RN and each found to need more hours than the RUGs system provides. Many of DRA's clients are totally dependent upon others for all of their activities of daily living, yet have been placed in a RUG that does not provide enough attendant care hours to adequately and safely meet their daily needs.

[5] Receipt of nutrition by means other than through the digestive system, i.e. tube feeding through a venous catheter.
[6] IV Medications, Suctioning, Tracheostomy care, or Ventilator or Respirator.

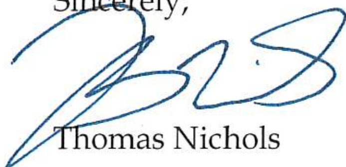
As a result of their RUG placement, DRA's clients have been forced to be without staffing for a large portion of the day, which has impacted their health and safety and placed them at greater risk for infections and pressure ulcers. DRA's clients are at risk of remaining soiled for the vast majority of the day. They are at risk of not being able to leave their beds or wheelchairs; they are at risk of not being able to communicate with others. They are at risk of missing life-saving breathing treatments, medications, and life-sustaining nutrition and hydration. DRA's clients have experienced increased stress as they worry about how they will be able to safely remain in the community if they are unable to obtain the needed assistance. They have had to consider institutionalization should the process not change to provide them with adequate attendant care hours, which they had previously been receiving until DHS changed to the RUG process.

Conclusion

These are the very real and very serious implications of a system that does not truly individualize a beneficiary's needs. The reality of DHS's use of the RUGs system, without the addition of nurse discretion, is that many individuals with disabilities are forced to choose between living in the community without sufficient assistance or to go into an institution. This is a reality that defeats the very purpose of this type of Medicaid waiver program and, in the end, results in care that is more costly to the State.

Moreover, DHS is in a unique position when it comes to the rulemaking process. It does not have to speculate with regard to the impact its change will have on individuals it serves. It has had a number of opportunities to hear the detrimental effect from the individuals themselves through the number of appeals and hearings that have occurred since it was originally implemented. Consequently, we urge DHS to take this opportunity to genuinely listen to the public comment offered to it regarding these extremely important services and adjust this rule to permit variation based on evaluation and assessment by medical care providers.

Sincerely,



Thomas Nichols
Managing Attorney