

Item #	Rule Cite Line #	Comment From	Comment	Analysis/ Recommendation
1.		Janet Kirwan SW Autism Research Center	<p>Concern with piece addressing Autism, in the past there were no points for autism only for the other three developmental diagnosis that were allowable for application. <u>My concern now is that it is still requiring children with autism meet a further set of criteria</u> and not just the diagnosis as they do for the points in cerebralpulsy, mental retardation and for epilepsy, those points are granted based on their diagnosis. There is a further scrutiny for children with autism; <u>my concern is about some of the questions, in particular the autism behavior questions. How were those criteria reached?</u></p> <p>The fact that we have the drop of the children that fall in the 18 month to 13 month group, the number of children who are eligible using the new PAS tool, you said were going to probably be offset by the number of children who were going to be eligible in the system prior to 12 months. Very few of our children with autism will be on the radar and applying for services under 12 months. <u>Just during that period where our children are most likely to be identified and the parents would be looking for services is the area where there is a drop.</u></p>	<p>The scoring algorithm for the draft revised tool was developed through a statistical analysis of data collected on 770 children. The purpose of the analysis was to identify the appropriate combination of variables for determining whether a child meets the federal standard of eligibility. The variables coupling Autism Spectrum Disorder with developmental milestones and behaviors were constructed as part of this process. The variables were reviewed for reasonableness by developmental pediatricians before being included in the algorithm.</p>
2.		Maureen Casey	<p>How are you determining or defining moderate versus severe versus profound mental retardation?</p> <p>The tools are not that precise for children under age 6 for IQ, in the way you are using specific things for children with autism and behavior, etc. I would suggest that needs to be looked at for kids your deeming cognitively impaired. It is interesting that cognition is not listed as one of the specific domains, so I am unsure if they are being caught up in the developmental milestones. As for IQ testing the tools are not that precise for children under the age of 6, I caution you to look at that.</p> <p>We are clearly concerned about a group of kids that we have historically not captured accurately and we are also aware of another group of kids that are having as much difficulty getting in, children with down syndrome, children with cardio facial syndrome, lots of kids with cognitive impairment are also not getting inside the system under age 5. We as a state are deciding that children under the age of 3 we are going to make changes about how we are providing those services and how we are paying for those services and we wouldn't want to leave those kids behind.</p> <p>Will there be training for screeners, support coordinators, and the advocates to attend once this is put together so we can have an accurate picture of what folks can expect and respond to parent concerns?</p> <p>I ask that AZEP is a part of this, because some of those kids that we</p>	<p>AHCCCS relies on the child's available medical records for the diagnoses.</p> <p>When the PAS revision is finalized and implemented,</p>

			<p>determine as AZEP only and are not accurately moved over to DD they stay in AZEP up to age 3 then pop up in DD at age 6. We want to make sure that we capture all the kids that need to be provided services.</p>	<p>AHCCCS will provide extensive training to its staff including PAS Assessors and physician consultants. In addition, AHCCCS will provide training to designated DES DDD staff, who will then provide direct training to its staff.</p> <p>As in the past, AHCCCS will provide an overview of the ALTCS eligibility criteria including the PAS for external groups upon request and as resources allow.</p>
3.		<p>Kristina Park  (would like a response to her comments)</p>	<p>Some of my concerns about the PAS, <u>is the vagueness of some of the questions as it stood in the past.</u> One of the questions asks if a child can take off their shoes and pants. Here in AZ many children wear sandals, flip flops. Developmentally there is a big difference between sneakers versus flip flops. Many of the families going through trying to answer the questions do not think about it in a developmentally form, they try to answer the questions correctly. I have noticed that from going through this and helping other parents that this is an emotionally and rough process since you must think and admit that you cannot control your child or child cannot do many things. You cannot focus on the positives that get you through day to day. In this process you have to be willing put everything on the table to a complete stranger since that is how you can get fair assessment of your child. When you are asked can your child take their shoes off, you need to ask what does this mean? Is it a shoe with laces, without, with Velcro. This is a very broad range. Many parents often assume that their child can do this but they cant. <u>So many times we need to understand that the question you are asking is what actually represents of what our child is capable of as well as what do you mean by this when you ask this.</u> There is a particular question, “Can a child turn pages?” and further asks “Can a child turn one page?”, but it needs to explain if its a paper page or cardboard page. Many of these families have to let their children get worse before they can qualify for services. <u>I am concerned that the part that you are keeping the same also needs to be reviewed. I am concerned whether it really is objective.</u> There are many kids that rely on us, most of the people that this affects do not know about this meeting, or do not have access getting to places like this. It’s a big burden. <u>I’m not seeing a lot of families here which concerns me; because every single family I have come in contact with this process has been a major stumbling block.</u> I want you to think about this as part of my information sharing with you.</p> <p>Written comment: PAS Tool review of questions need clarification: Question #8, two or more emotions (non-emotion = not emotion) Question #16, five examples of babble</p>	<p>The draft revised tool contains 101 developmental milestones, versus 50 on the existing tools. The revised and expanded milestones were selected in part for their precision and clarity. Many were based on questions from nationally-recognized and validated instruments.</p> <p>During the pilot study conducted on 770 children, parents/caregivers were able to compare the current and revised tools. All of the parents/caregivers who expressed an opinion preferred the revised tool over the current instrument.</p> <p>Extensive training, including refresher training, is provided to all PAS Assessors. Refresher training is based on results of ongoing quality control reviews conducted on completed PAS. Quality control reviews will be increased following implementation of changes to the PAS tool to ensure thorough understanding and proper use of the tool.</p>

		<p>Question #25, when playing with sounds, does your child make grunting, growling or deep-toned sounds?  Question #32, cloth, board, paper book – different developmental developments.  Question #34, stack blocks (can you model?)  Question #42, interest in other children? (don't understand)  Question #54, play near other children? Child gets overwhelmed.  Question #68, Paper pages?  Question #78, Stuffs mouth – as example  Question #94, gross versus fine skills, explain lever vs. know doors to be opened</p> <p>Wonderful changes:  Question #18, Patta cake!  Question #26, coo, laugh, pleasurable sounds! be cautious to indicate that it is not when tickled.  Question #53, copy activities!  Question #62, Sleep less than 8 hours, be cautious to indicate trying to sleep 2-3 hours.  Question #85 ! in, on, under.</p>	<p>Assessors are specifically trained to elicit accurate information regarding performance and behaviors, while understanding how difficult this can be for families.</p> <p>The examples provided in the written comment will be considered for use in training.</p>
4.	Chris Smith SW Research Center (would like a response to comments)	<p>Why is there the additional threshold for individuals with an autism spectrum, to have a diagnosis and then also meet the criteria of specific items from the tool? What is the rational behind that?</p> <p>In addition to autism, the diagnostic information needs to be enhanced by a score of specific items in the critical.</p> <p>You stated in the presentation that you believed that the effects would be neutral on the targeted population, how do you feel that this will allow more children to be in the system that need to be in the system if the</p>	<p>The scoring algorithm for the draft revised tool was developed through a statistical analysis of data collected on 770 children. The purpose of the analysis was to identify the appropriate combination of variables for determining whether a child meets the federal standard of eligibility. The variables coupling Autism Spectrum Disorder with developmental milestones and behaviors were constructed as part of this process. The variables were reviewed for reasonableness by developmental pediatricians before being included in the algorithm.</p> <p>An analysis of the projected impact of the revised tool found that it would be neutral at the program level in year 1. The analysis also found variation within specific age cohorts, with a projected increase in eligibility by score for children under 12 months of age and 48 months and older, and a decrease in children 36 – 47 months. Over time, the net result at the program level may be an increase in eligible customers, as larger numbers of young children continue to enter and remain in the program.</p>

		<p>effect is neutral?</p> <p><u>Written comment received by 5pm 10/12/10:</u> As a result of the public hearing regarding the PAS revisions, please accept the following comments for public record:</p> <p>The federal standard for coverage is an accrual of 40 points on the PAS tool. Cerebral Palsy, Epilepsy, Mental Retardation, and autism spectrum disorders all get baseline point values for meeting criteria for the diagnosis. According to the guidelines of the revised PAS tool to qualify for coverage by AHCCCS and individual who has met criteria for an autism spectrum disorder and accrues 40 points on the PAS tool (meeting the federal standard) must also have accrued points from specific items in the PAS. <u>Why is this additional requirement necessary before becoming eligible for coverage from AHCCCS?</u></p> <p>These criteria become particularly problematic for the Autism + Behaviors, Children 30 to 35 months category. Children in this category need to exhibit an additional 3 out of 4 behaviors and the behaviors are not consistent with current diagnostic criteria for autism. Thus, very impaired children with autism, who will meet the federal standard of 40 points, require institutionalization (either in a facility or a home), who do not exhibit these behaviors will not be eligible for coverage. These items were selected because they were strongly correlated with autism in the pilot study, but <u>correlation does not explain causation (of severity, in this case). The purpose and implications of the selected of correlated items is unclear.</u></p> <p><u>We suggest removing the additional item requirements beyond the criteria for the federal standard of 40 points on the PAS tool.</u></p> <p>Additionally, because the deficits associated with an early identification of autism spectrum disorder can be subtle at first (and then lead to greater impairments) <u>we suggest that PAS assessors have some basic training or education specifically on the presentation of early warning signs for</u></p>	<p>Please see the response to Item #1. Also, please note that applicants are not required to accrue points from specific items in order to meet the eligibility standard, but only to accrue 40 or more points from any combination of algorithm variables in order to be found eligible by score.</p> <p>Information about the different developmental disabilities is covered in PAS assessor training. To clarify, PAS assessors are identifying children who</p>
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			<p><u>autism.</u> We believe this is imperative because of the reorganization of the items in the PAS tool, it appears and your data show, that it may be more difficult for younger children with an autism spectrum disorder to meet the federal standard for coverage.</p>	<p>require an institutional level of care; they are not assessing for early warning signs of any particular condition, which would not indicate an institutional level of care. (also referred to as immediate risk for institutionalization.)</p>
5.	Leighssa Pearson-Dobrosky Health Group	<p>My concern when we have questions that are yes or no questions that are procedural, and I have a child that can do 3 out of 6 or 2 out of 8, mom or dad might say the child can perform toiletry skills, is the assessor going to come in and say can he do this independently? <u>Can we get these questions more broken down</u>, such as Can he pull up his pants? Can he pull down his pants? Can he do his fasteners? Etc. We have a very long chain of behaviors that are needed to do something that is procedural. A yes or no is not specific enough for something that needs to be broken down.</p> <p>Another concern is the number of words that a child may have. A child may have 150-200 words that are all objects, but they cannot tell you what they are for, color, what to do with them, can't ask for them, and some of the more important phrases missed are "I am hungry", "I am tired", "I am in pain". <u>So if we can break things down more to ensure they have functional communication</u>, such as, can they request things, comment, ask questions, may be more helpful to assess the child.</p>	<p>Please see the response to Item #3. As indicated, the revised tool strives to be precise in its wording and does seek to break tasks into discrete steps. For example, the current PAS asks a single question, "Does s/he remove her/his own shoes and pants?" The revised tool asks, "Does your child pull up clothing with elastic waistbands (for example underwear or sweatpants)?" and "Does your child put shoes on correct feet (does not need to tie laces)?"</p>	
			<b>Written Comments</b>	
6.	De Freedman	<p>I respectfully submit my comments to the 2010 proposed PAS Tool revision:</p> <p>As a taxpayer who just spent 8 months volunteering as a member of the AZ DDD Sustainability Workgroup at the request of AZ DES Director Neal Young, <u>I am dismayed at the secretive process used by AHCCCS to create these proposed state rule changes that amend the current PAS Tool.</u> AHCCCS employees Alan Schafer and Theresa Gonzales also were members of the DDD Sustainability Workgroup and were present, if my memory serves correctly, on more than one occasion when amending the current PAS Tool for children with developmental disabilities during a few meetings of the DDD Sustainability Workgroup was discussed. It was the group consensus, based upon prior conversations with AHCCCS employees and the contributions of Alan Schafer and Theresa Gonzales when present, that the only known way to amend the PAS Tool was by legislation which is not politically feasible at this time. For that reason, revision of the PAS Tool was not discussed extensively by the DDD Sustainability Workgroup nor were any recommendations made in our report to Neal Young even though it was the consensus of the DDD Sustainability Workgroup that the current PAS Tool is seriously out of date given what has been learned since 1996</p>	<p>The rulemaking has been conducted consistent with all the notice and publication requirements of state law.</p> <p>While the standard for eligibility has not changed, the PAS tool has been updated to improve accuracy, consistency and ease of administration.</p>	

about child development, especially for children 0-3. Never during their time meeting with the DDD Sustainability Workgroup did either Alan Schafer or Theresa Gonzales mention that AHCCCS had been working on revising the PAS Tool since 2009 nor that those revisions would be accomplished by a state rule change.

Instead, on September 9, 2010 I received a forwarded email from Mariaelena Ugarte of AHCCCS sent to another member of the DDD Sustainability Workgroup announcing the AHCCCS PAS Tool revision to be accomplished by proposed State rule change. It is my understanding that not only were no DES/DDD employees (nor any other DES employees) involved in the AHCCCS PAS Tool Revision Project, but that they were as surprised as I was to learn that AHCCCS had been working on this project since 2009. I do not understand why no DDD employees, those AZ state employees who best know what should be included in the PAS Tool because they actually are the individuals responsible for overseeing the AZ state services and therapies for children with developmental disabilities, were never consulted. It is my understanding that not even DDD Medical Director Robert Klaehn, MD, was consulted.

As the parent of 9 year old child with autism who has qualified for ALTCS since September 1, 2003, I know the inadequacies the ALTCS qualification process including the current PAS Tool because I experienced the process first hand and I have shared experiences with other parents raising children with developmental disabilities, especially autism. I am dismayed that I nor any other AZ taxpayers with similar experiences were never consulted by AHCCCS regarding its PAS Tool Revision Project.

As the Secretary of the AZ Autism Coalition (<http://www.azautism.org>), I would have informed AHCCCS that Coalition members have been studying a PAS Tool revision for the past several years and in fact have a draft proposal that we would gladly share with AHCCCS. Our membership includes over 150 stakeholders of the AZ Autism Community including parents, services providers, university professors, school personnel, psychologists, developmental pediatricians and representatives of ADE, DDD and DHS/BMH, all of whom are eager to share their experience and expertise with AHCCCS, but were never asked.

Upon learning of the AHCCCS PAS Tool Revision Project, I immediately emailed Mariaelena Ugarte of AHCCCS and requested the "the complete development documents including, but not limited to, the data collection, reliability analysis and development of a scoring algorithm for the 2010 proposed PAS Tool revision, notice of which was

This workgroup is unrelated to the rulemaking.

This revision to the PAS tool was conducted in the same manner as previous revisions to the tools used for people who are elderly/ physically disabled and those used for people with developmental disabilities. Our consulting physicians, who also practice in the community, are involved in all PAS tool revisions, along with other experts in the particular field.

The Administration engaged the services of an independent consultant to conduct a redesign of the PAS instrument used for children under 6, including a survey and analysis of existing valid and reliable tools for assessing functional impairments and input from developmental experts, with the goal of identifying reliable indicia of when a child is at immediate risk of institutionalization. This is a separate question from how best to provide services to children who have been determined to be at immediate risk of institutionalization.

Anecdotal information regarding individual children with a developmental disability does not constitute objective statistically valid assessment criteria with respect to the question of whether the child is at risk of immediate institutionalization.

			<p>posted on 9/10/2010 on the AHCCCS website at <a href="http://www.azahcccs.gov/reporting/Downloads/ProposedStateRules/NOPRFinal_PASool.pdf">http://www.azahcccs.gov/reporting/Downloads/ProposedStateRules/NOPRFinal_PASool.pdf</a>. ” I am disappointed with the documentation I received. I still await the ACTUAL (rather than a prepared summary report and powerpoint presentations) “data collection, reliability analysis and development of a scoring algorithm” before I can address whether the 2010 proposed PAS Tool revision is what it claims to be. According to the materials sent to me by Mariaelena Ugarte, AHCCCS did an internal “mini project” of the proposed PAS Tool revision by analyzing 6 cases. The standard practice for such a project certainly constitutes the review of many more than 6 cases.</p> <p>It is my experience that nothing conceived in total darkness can be trusted. Forgive me if I am skeptical of the 2010 proposed PAS Tool revision as I have no idea which other state PASSRs were used as models or the identities, let alone qualifications, of the individuals who did the analysis. While I know David Hirsch, MD, and respect him, it is my understanding that his participation in the development and testing of the 2010 proposed PAS Tool revision was finished in 2009 and very limited. <u>I respectfully request that before AHCCCS proceed any further with the 2010 proposed PAS Tool revision that AZ stakeholder be consulted and that that the 2010 proposed PAS Tool revision actually be tested fully, certainly beyond 6 cases, to show that it will not adversely affect the ALTCS eligibility of AZ children with developmental disabilities.</u></p> <p>Contrary to AHCCCS claims, it is my experience that the <u>PAS Tool is a very subjective eligibility tool rather than an objective tool</u>. Those of us who have experienced the determination of ALTCS eligibility for our children with developmental disabilities, especially autism, using the PAS Tool are all too aware of the subjectivity of the PAS Tool. Without proper training for AHCCCS personnel that will not change regardless of whether the 2010 proposed PAS Tool revision is a better tool to determine ALTCS eligibility.</p>	<p>The information requested was sent via email multiple times with a separate final request to confirm receipt of the information. The Administration did not receive any indication that the information sent was not received.</p> <p>The specific information on cases cannot be shared under federal and state privacy laws.</p> <p>In a mini pilot eight assessors looked at 6 cases each for a total of 48 cases in order to refine questions. In addition, in the full pilot at least 18 assessors completed assessments on approximately 770 cases where both the current and new tool were administered to establish the reliability of the new tool.</p> <p>The questions used in the PAS tool are derived from nationally recognized developmental assessment tools. In the Administration’s opinion these are the most objective instruments available.</p>
8.		Andrea Ford	<p>In follow up to the hearing today on the PAS proposed (and current) tool, here are our concerns:</p> <p>1/ Does not give uniform assessment for all age groups - medical points are different (attainable per age group 3-5 yr and 0-5 are being discriminated against).</p> <p>2/ Loss of skills is not given points for 0-5 age group when they lose previously attained milestones as an older (over 12 year old would or adult).</p>	<p>The objective of the tool is to measure functional limitations as measured against recognized developmental milestones that are tied to these age groups.</p> <p>Regression is captured in the accumulative design of the developmental questions by age groups.</p> <p>Use of the PAS tool does not constitute violation of any</p>

			<p>3/ It discriminates on the basis of disability - MR gets medical points and only a special diet gets medical points for a 3-5 year old/0-5 year old). Discriminatory on the basis on type of disability.</p> <p>4/ Waiver 1115 general requirements STC's require the State to comply with ADA and all federal anti-discrimination laws.</p> <p>5/ EPSDT is not met if young children are found in State screenings to have a developmental disability (eg:autism) and the condition is not treated because they are denied ALTCS for lack of 40 and above points, or, not being considered in the State's opinion to be at immediate risk of institutionalization.</p> <p>Please give our parent advocacy written notice that these comments have been received and will be considered.</p>	<p>discrimination laws. Federal law requires that as a condition of eligibility for the receipt of certain long-term care and Home Community Based Services (HCBS), that the administration must limit eligibility for those services to persons at immediate risk of institutionalization. Persons at immediate risk of institutionalization require an institutional level of care. The risk of institutionalization is measured by the degree of disability.</p> <p>Use of the PAS tool does not constitute violation of any discrimination laws.</p> <p>The requirements of the Early Periodic Screening Diagnosis and Treatment (EPSDT) program apply to persons under the age of 21 who are determined eligible for title XIX. That EPSDT requirement has no application to the eligibility determination process itself.</p>
9.	Brian Lensch DES		<p>In reviewing the public document there are several places throughout which make reference to individuals as a <u>“disability”</u> rather than <u>“people first”</u> language (person with a disability).</p> <p>R9-28-301 Page 9 “DD” means developmentally disabled: <u>better to state</u> a person with a developmental disability.</p> <p>R9-28-303 Page 11; A.1. “..for a physically disabled applicant or member..”: <u>better to state</u> “... for an applicant or member with a physical disability...” Page 11: A.1. “... a physically disabled child...” <u>better to state</u> “...a child with a physical disability...” Page 11: A.3. “...an applicant or member who is DD...” better to state “... an applicant or member who has a DD...” This occurs approximately 9 times through out the document. Page 12: G.7 &amp; 8 “...applicant or member is a physically disabled child...” better to state “ ... applicant or member is a child with a physical disability...”</p> <p>R9-28-305 Page 15: C.1.a “Each response is assigned a scored a number of points....” Should revise to read “Each response is assigned a</p>	<p>Disagree with recommended changes due to the existence of the defined term “DD” throughout Chapter 28, not merely in rules R9-28-301, R9-28-303, and R9-28-305. To revise the meaning in the subject rules would create inconsistency with other rules using the terminology.</p>

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